Quality of Life
in Head and Neck Cancer Patients
and Their Spouses

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ABSTRACT

TITLE: **Quality of Life in Head and Neck Cancer Patients and Their Spouses**

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Although researchers have studied the psychological and psychosocial effects of radical surgery on head and neck cancer patients, little empirical data exist regarding predictors of quality of life in head and neck cancer patients and their spouses in the face of this devastating illness. The goal of this study was to improve our understanding of the experiences of head and neck cancer patients and their spouses and of variations in quality of life in head and neck cancer patients and their spouses during the first 6 years after surgery. This study used a descriptive correlational design to describe the self-reported experiences of head and neck cancer patients and their spouses and to examine the association between illness-related, patient, spouse, and dyadic variables and quality of life for head and neck cancer patients and their spouses. Measures were obtained at one point in time during the first 6 years after initial surgery for head and neck cancer. Questionnaires were mailed to 125 patients and their spouses, along with a letter explaining the study, a letter of support from the surgeons, and a consent form. The sample consisted of 33 patients and their 33 spouses, 7 patients with no linked spouse data, and 7 spouses with no linked patient data. Descriptive statistics were used to analyze study data. Major findings include the following. Patients reported the highest satisfaction with life on disease-specific items relating to pain, swallowing, and shoulder disability. Chewing was ranked as the most difficult issue for them. Patients reported being most satisfied with life on a global QOL Scale in the area relating to relationships with close family members and friends. Spouses also rated this item among the highest, but indicated that having and rearing children was the most satisfying. Responses relating to perceived stigma indicated that more patients have difficulty relating to their appearance, having to “break the ice” on social occasions, and sensing others’ perceptions of the illness. More spouses reported difficulty in relating to others’ being embarrassed to ask about the patient’s illness, and sensing that others did not know how to react to the patient’s illness. Items ranked the highest by both patients and spouses related to others’ judging them, or others’ reactions to the illness. A series of hierarchical multiple regression equations using 2 different dependent variables revealed the following. In the disease-specific model for patients, depression accounted for the greatest increment in the explained variance ($R^2\ \Delta=12.5\%$), after controlling for 3 other predictors. In the global QOL model for patients, the disease-specific scale accounted for the greatest increment in the explained variance in global QOL ($R^2\ \Delta=22.1\%$), followed by female gender (13.8%). In the global QOL model for spouses, depression accounted for the greatest increment in the explained variance ($R^2\ \Delta=27.7\%$), followed by mutuality ($R^2\ \Delta=9.2\%$) and SOC ($R^2\ \Delta=8.2\%$). Findings of this study confirm the importance of the influence of functional difficulties on patients’ quality of life, depression on patients’ and spouses’ quality of life, and the marital relationship on spouses’ quality of life. In addition, these findings underscore the importance of the need for clinicians to attend to issues salient to spouses of head and neck cancer patients as well.

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Chapter 1

Introduction

Cancer is the second leading cause of morbidity and mortality for adults in the U.S. (Greenlee, Murray, Bolden & Wingo, 2000). Although head and neck cancer accounts for only about 5% of all malignancies in the U.S. (Vaughan, Fitzgerald, Vlock, Vergo & Costello, 1996), the treatments, such as surgery or radiation, may result in severe physical and emotional difficulties for the patients. In the U.S. in 1998, approximately 41,400 new cases of cancer of the oral cavity, pharynx, and larynx occurred, and there were about 12,300 deaths from these cancers (Landis, Murray, Bolden & Wingo, 1998). These numbers are expected to rise as the population ages (Alvi, Myers & Johnson, 1996), because the use of smokeless tobacco has increased, and more women are beginning to smoke than in the past (Vaughan et al., 1996).

Head and neck cancers are usually caused from smoking cigarettes, cigars or pipes, or the use of smokeless tobacco--the use of snuff or chewing tobacco (American Joint Committee on Cancer, 1992). Frequently, it is the combination of long-term smoking and drinking alcohol. Other possible causes include ultraviolet rays, poor oral hygiene, mechanical irritation, dietary factors (nutritional deficiencies or the ingestion of salt-cured fish), or environmental toxins (e.g., smoke from burning wood, grass and exhaust fumes from rubber plants) (Fischer, 1996).

Many head and neck tumors are not detected until later stages–stages III and IV (Shaha & Strong, 1995; Strong & Spiro, 1996). Late detection results in a poorer prognosis (Alvi, Myers & Johnson, 1996) and a greater chance for recurrence (Campbell, Marbella & Layde, 2000; Goodwin, 2000). One of the objectives of Healthy People 2010 is the reduction of deaths from oral and pharyngeal cancer in persons 45-74 (U.S. Department of Health and Human Services, 1997).

The effects of head and neck cancer surgery on patients are well documented (Bronheim, Strain, & Biller, 1991; Deleyiannis & Weymuller, 1996; Dropkin, 1999; Gamba et al, 1992; Sherman & Simonton-Atchley, 1996). Some of the physical and functional difficulties that may occur after treatment for head and neck cancer include problems with speaking, chewing, swallowing, dry mouth (xerostomia), pain and shoulder immobility. Although great strides have been made in reconstructive surgeries, facial disfigurement may also result. The area of the face is of great importance in interpersonal relationships (Bronheim, 1994; Schilder, 1935).

Cancer is an experience that affects the whole family, not just the patient (Lewis, 1998). Little is known about the effects of head and neck cancer on the marital relationship or on the quality of life (QOL) of the spouse. Because spouses are the main support for cancer patients, their experience is important to understand.

The purpose of this research was (a) to describe the self-reported experiences of head and neck cancer patients and their spouses; and (b) improve our understanding of the variations in QOL in head and neck cancer patients and their spouses during the first 6 years after surgery. This cross sectional study described the self-reported experiences of head and neck cancer patients and their spouses, and examined how illness-related, patient, spouse, and dyadic variables predicted the QOL of patients and spouses.

Chapter 2

Review of Literature

Figure 1 represents a conceptual model of the study variables. The concepts included in the model were selected because of their relevance to the situation of families in which a member has had surgery for head and neck cancer. Illness-related variables include disease severity (stage II, III or IV), time since initial surgery, treatment intensity, and recurrence of disease. Patient variables include age, gender, depression, stigma, and sense of coherence. Spouse variables include age, gender, depression, stigma, and sense of coherence. Dyadic variables include mutuality and dyadic adjustment. Patient and spouse QOL are the outcome variables.

Literature regarding the outcome variable, QOL, is reviewed first, followed by patient characteristics variables, spouse characteristics variables, illness-related variables, dyadic variables, and a discussion of the selection of predictors. Finally, the specific aims and related hypotheses are described.

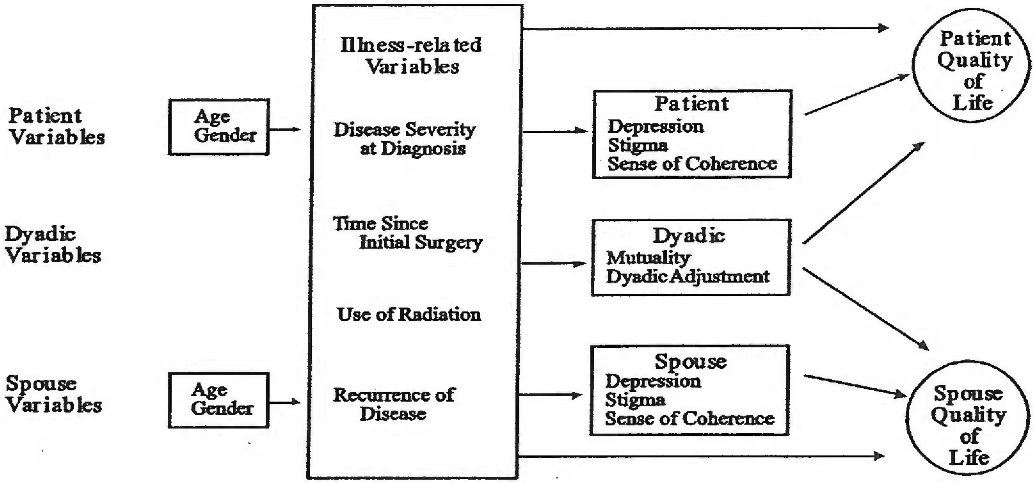


Figure 1. CONCEPTUAL MODEL:
Quality of Life in Head and Neck Cancer Patients and Their Spouses

Quality of Life

Historical background. Many articles on cancer dating back to the 1940s have alluded to the concept of QOL in various forms. Traditionally, objective outcomes such as survival rates, treatment toxicity, and physical function have been the endpoints in research (Padilla & Frank-Stromborg, 1997). In a medical context, Karnofsky and Burchenal (1949) had been studying QOL in the oncology population in the 1940's by looking objectively at the functional status of patients. Other areas such as cardiology and psychiatry have also focused on the effects of new treatments and procedures.

The term QOL became better known in America in 1960 in an essay submitted to President Dwight D. Eisenhower's Commission on National Goals. The speaker reported: "...a society which puts a value on the quality of its national life will want to act resolutely" (cited in Morton, 1995, p. 1031). In the 1960s and 70s, social and political scientists desired to know and understand how people felt about the QOL in a particular community. In addition, QOL was increasingly used in the health sciences to determine the most cost-effective manner of therapy (Allison, Locker & Feine, 1997).

During the last 10 to 15 years there has been increasing interest in assessing psychosocial and functional adjustments to illness. Today, QOL is an important outcome variable in many oncology clinical trials. More exploratory work is being done in this area as well. According to Cella (1992), measuring quality of life has become a necessary component in oncology research. Baker (1995) echoes this view in her comment on the importance of including QOL measures in current cancer studies: "...we have to defend not doing it" (p. 712).

Conceptual definitions. Just as a wide array of concepts may be included under the umbrella construct of QOL, so may a number of definitions exist. Young and Longman (1983) define QOL as "perceived satisfaction with present life circumstances" (p. 220), while Ragsdale, Kotarba and Morrow (1992) suggest it represents "the relative effectiveness of the patient's management style in solving problems associated with being 'seriously sick'" (p. 260). Another definition by Ferrans and Powers (1992) is this: "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important" (p. 29). Some of the reasons that many definitions exist may be due to diverse philosophies of investigators, different goals of care, and the variety of diseases and treatments that are included in the research studies.

Operational definitions. Operational definitions are measures or observations of the indicators of a concept (Polit & Hungler, 1993). In a review of theoretical implications of QOL in oncology nursing research, Mast (1995) concludes that, because of the ambiguity surrounding QOL, decisions regarding its use have been pragmatic rather than theory-based. She describes three approaches to operational definition--measures which are unidimensional, multidimensional single-scale, or multiple separate measures. Unidimensional scales usually ask a single question, relating to overall QOL. The dilemma in this approach is that it is difficult to determine the domains that accounted for the satisfaction or dissatisfaction. The multidimensional single-scale approach utilizes multiple domains, which allow nurse researchers to include disease-and treatment-specific indicators. However, they are difficult to compare across studies, instruments may not be specific, variables may overlap, and comprehensiveness in the instrument can be problematic.

A trend in QOL methodologic studies is the use of multiple scales. For example, using a disease-specific QOL scale along with a global QOL scale may provide comprehensiveness in terms of including salient domains, and may also be responsive to the impact of a particular disease or treatment and its sequelae. More indicators may be included by using multiple scales, and both subjective data may be obtained from patients, as well as objective data from chart review, caregivers, or health care professionals. Adding to subject burden is another potential problem. In a review of QOL studies in oncology, King and her colleagues (1997) concluded that a great deal of the recent literature has concentrated on defining the content of the large array of QOL instruments.

Who should assess QOL? In oncology studies, it has traditionally been the physician who has routinely rated the performance of the patient. However several studies document discrepancies between patient's self-ratings and ratings determined by physicians (Hutchinson, Boyd & Feinstein, 1979; Pearlman & Uhlmann, 1988; Schag, Henrich & Ganz, 1984). Consequently, the current trend is to use patient self-report (Morton, 1995). Following an extensive review of the literature of QOL relating to cancer, King and colleagues (1997) suggested that the major concerns of survivors following treatment be explored from their perspective.

Instruments to measure QOL and similar concepts. A few of the concepts similar to QOL in clinical research include life satisfaction (Morton, 1995) and well-being (Ferrans, 1990), and, for family members, caregiver burden (Zarit, Reever, & Bach-Peterson, 1980). Some of the instruments used in measuring QOL in clinical research include:

- the Modified Quality of Life Scale (QOLS) (Burckhardt, Woods, Schultz, & Ziebarth, 1989; Flanagan, 1982); and

- the Medical Outcomes Study Short-form 36 (MOS-SF36) (Ware & Sherbourne, 1992).

Some of the disease-specific instruments used in head and neck cancer research include:

- the Functional Assessment of Cancer Therapy Scale–Head and Neck (Cella et al., 1993).
- the Performance Status Scale for Head and Neck Cancer (List, Ritter-Sterr, & Lansky, 1990);
- the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Head and Neck Module (Bjordal & Kaasa, 1992); and
- the University of Washington Quality of Life Scale (Hassan & Weymuller, (1993).

Some of the instruments used in oncology research include:

- the Quality of Life Index-Cancer Version (QLI-CV) (Ferrans & Powers, 1985);
- Quality of Life-Bone Marrow Transplant (QOL-BMT) (Ferrell et al., 1992); and
- the Functional Assessment of Cancer Therapy Scale–General Measure (Cella et al., 1993).

Although there is a selection of reliable and valid instruments for use measuring disease-specific QOL and global QOL, the decision for the choice of instruments in this study (the UW-QOL Scale and the QOL Scale) was based on decreasing respondent burden, as well as capturing the experience of head and neck cancer patients and their spouses. They are short, understandable, and the response options are clearly differentiated. The comments from the experts who piloted the instruments formed the basis for these decisions as well.

Quality of life is particularly relevant for patients who experience head and neck cancer (Gotay & Moore, 1992; Morton, 1995; Weymuller et al, 2000), and is usually included in studies of this population (Deleyiannis & Weymuller, 1996; List, 2000). Disease-specific QOL instruments are recommended when global assessments do not capture the unique impact of the disease on the person (Hassan & Weymuller, 1993; List, 2000; List, et al, 2000; Netscher, Meade, Goodman, Alford & Stewart, 2000; Sherman et al, 2000). Persons with head and neck cancer surgery have problems socializing, eating in public, speaking, and swallowing; many patients also have facial disfigurement and shoulder pain (Karnell, Funk, & Hoffman, 2000). A disease-specific measure of QOL in this patient population should be responsive to the impact of these problems. Because the disease-related QOL patterns are not known for this group, these patterns should be explored.

Because nurses are concerned with the "whole patient," QOL is an appropriate outcome (Dow, Ferrell, Haberman & Eaton, 1999; Padilla & Grant, 1985). While numerous definitions for QOL exist, there is consensus that the construct is multidimensional and evolving (Dow et al, 1999; King et al., 1997). The definition that was used for this study is "the degree of satisfaction with the perceived life circumstances" Young & Longman, 1983, p. 220). Using a similar definition, Burckhardt (1985) found that 46% of the variance in QOL in 94 adults with arthritis was explained by four significant predictors: greater social support, negative attitude towards illness, higher self-esteem, and higher internal control over health.

As cancer treatment technology becomes more refined and people live longer, exploring factors that negatively or positively affect QOL will be an important part of nursing research (King et al, 1997). This study was intended to bring insight into the issues that head and neck cancer patients and their spouses believe to be salient to their experience and predictors that enhance or diminish their QOL.

Illness-Related Variables

Four illness-related variables were examined in the study and include: (a) disease severity at diagnosis (stage II, III, or IV); (b) time since initial surgery (in years); (c) treatment intensity in three ordered steps: (1) surgery alone, (2) surgery plus radiation / OR chemotherapy, and (3) surgery plus radiation plus chemotherapy; and (d) recurrence of disease (a dichotomous variable).

Disease severity at diagnosis. Tumors of the head and neck are categorized by their site, size, surrounding lymph node involvement, and metastasis (Beahrs, Henson, Hutter, & Kennedy, 1992). Radical neck dissection is often necessary when the tumor has invaded the cervical lymph nodes (Alvi, Myers, & Johnson, 1996; Shaha & Strong, 1995; Sisson & Lerrick, 1996). Tumor sites include the oral cavity, pharynx, (nasopharynx, oropharynx, and hypopharynx), larynx, and the paranasal sinuses (American Joint Committee on Cancer, 1992). More advanced cancers (stages III and IV) result in the greatest amount of facial disfigurement and dysfunction (de Graeff et al, 1999; Piccirillo & Pugliano, 1996; Vaughan et al, 1996). In a study of 72 head and neck cancer patients 3 years after surgery, Campbell, Marbella and Layde (2000) reported that patients with more advanced stages of cancer had lower QOL scores, especially in the areas of self-perceived disfigurement, employment, chewing ability and speech.

Time since initial surgery. Although each individual's experience is unique, it takes about 6 months to fully realize the functional and psychosocial effects of head and neck cancer surgery (Gamba et al, 1992). Quality of life may fluctuate, depending upon the course of the disease and its treatments (Bronheim, Strain, & Biller, 1991; Deleyiannis & Weymuller, 1996; Hammerlid et al., 1997).

In a summary of QOL studies, List (2000) concluded that time is an important factor to consider in planning future research because patients usually report a decrease in QOL around the time of treatments (e.g., radiation, surgery). In a 1-year prospective, longitudinal study, 35 head and neck cancer patients completed mailed surveys at six points in time (Hammerlid et al, 1997). A pattern of increasing symptoms, and decreasing QOL, during and just after surgery, radiation, or chemotherapy was identified. In a study by Hassan and Weymuller (1993), 75 patients completed QOL questionnaires before any treatment, immediately after surgery and/or radiation, and 3 months after surgery and/or radiation. Quality of life declined during the period of treatment, but recovered by 3 months posttreatment. The results of these studies underscore the importance of using time since surgery as a predictor of QOL and call for examining QOL beyond 1 year of diagnosis.

Treatment intensity. Surgery and radiation are the two main treatments for head and neck cancer (Alvi, Myers, & Johnson, 1996; Johnson & Myers, 1996; Strong & Spiro, 1996). In a recent study of 21 head and neck cancer patients treated with radiation only, Allal, Dulguerov, Bieri, Lehmann and Kurtz (2000) reported that QOL was significantly negatively affected, primarily due to radiation induced xerostomia. In a prospective study of 65 laryngeal cancer patients treated with radiation alone, de Graeff and colleagues (1999) determined that, at 6 months, there was a significant deterioration of physical functioning (swallowing, smelling, speaking) and QOL scores, and an increase in symptoms (dry mouth, sticky saliva, fatigue) that were directly due to the effects of the radiation. At 12 months, these symptoms were improved, but still worse in patients with more advanced stages of disease. The prevalence of psychological distress in 205 long-term (7-11 years) survivors of head and neck cancer also treated with radiation only was high (Bjordal & Kaasa, 1995).

Recurrence of disease. Little research has been done which looks at recurrence of disease and QOL outcomes (deBoer et al., 1999). Oncologic studies reviewed pertained to fear of recurrence and death (Welch-McCaffrey et al., 1989), married couples' experience with breast cancer recurrence (Lewis & Deal, 1995), and symptoms in relation to recurrence (Forbes, 1997). A synthesis of cancer recurrence studies by Lewis & Deal suggests that recurrence may be more stressful than the initial diagnosis, with worse symptoms (Forbes). Recurrence of head and neck cancer at the primary site occurs in approximately 20% to 30% of patients (Goodwin, 2000). In this study, recurrence was indicated by whether or not the same cancer had returned since the initial surgery.

Patient and Spouse Characteristics

Age, gender, depression, stigma, and sense of coherence are the variables included in this section.

Age. The risk of head and neck cancer increases markedly with age. Squamous cell carcinoma of the head and neck is most common and primarily affects persons in the fifth to eighth decades of life (American Cancer Society, 1998; Day, 1996). Persons over 50 years of age are more likely to have advanced tumors and second primary tumors (Shaha & Strong, 1995). Age predicts QOL and the similar concept of well-being, but the direction of association varies across studies. In a 13-nation survey of well-being in four age groups, respondents 50 and over scored higher on satisfaction with human relations and material needs than respondents in younger age groups (Butt & Beiser, 1987). Older cancer patients reported significantly better QOL than younger patients (Wan, Counte, & Cella, 1997). However, older post MI patients (Conn, Taylor, & Abele, 1991) and patients over 70 years of age after open heart surgery (Chocran et al., 1996) reported lower QOL than younger patients.

Gender. Female cancer patients report lower QOL than males. In a study of 687 long-term cancer survivors, females had significantly poorer QOL than males (Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995). Females also reported significantly lower QOL after open heart surgery (Chocran et al, 1996). In this study, it was hypothesized that female head and neck cancer patients would report a lower QOL than the male patients.

Depression. Many individuals with cancer suffer with depression (Evans et al, 1999). Head and neck cancers are associated with higher prevalence of and more severe depression than other cancers (Goodwin, 1982; Morton, Davies, Baker, & Stell, 1984). They are among the most emotionally traumatic of all cancers (Bronheim, Strain, & Biller, 1991). In their review of the literature, Pruyn and colleagues (1986) concluded that depression was part of the clinical picture of head and neck cancer, and that support from family and friends ameliorated its effects. In a study of 110 patients who had a laryngectomy or disfiguring facial cancer surgery 2 to 6 years before, 62% reported feelings of depression (de Boer et al, 1995). Based on these findings, depression was selected as a predictor of QOL for this study and hypothesized to be negatively related to QOL.

Stigma. Because severe facial disfigurement and functional disabilities may result from surgical resection of head and neck tumors (Davis, Roumanas, & Nishimura, 1997), changes occur in how the patient views him or herself and how others perceive him or her (Goffman, 1963). Stigma is described as a feeling of disgrace by a person who has a condition or disease (Stahly, 1988). Spouses, because of their closeness with the patient, may experience many of the same feelings as the patient. Goffman suggested that close family members acquire a "courtesy stigma" because of their affiliation with the disfigured person, and that they, as well as the ill person, must learn new strategies to manage the condition.

Stigma has been correlated with QOL in cancer patients. In a study of 60 abdominal and thoracic cancer patients, Koller and colleagues (1996) found that experienced stigma (using a scale they developed for the study) was positively associated with global QOL. Higher scores on their stigma scale reflected more stigma; higher scores on QOL scale indicated worse QOL. MacDonald and Anderson (1984) examined the effects of stigma on 420 rectal cancer patients, 265 of whom had a permanent colostomy. Using poor physical health, poor emotional health and poor social health as indicators for QOL, they found that stigma was correlated with each of the 3 indicators of QOL in individuals with and without a colostomy. In a Canadian study of 51 laryngectomy patients, Devins, Stam and Koopmans (1994) found that, although the great majority of them (84%) had achieved the recovery of speech, perceived stigma was correlated with life happiness ($r=-.33$; $p<.05$). It was hypothesized that stigma would be negatively related to QOL in this study.

Sense of coherence. Sense of coherence (SOC) is the key construct in Antonovsky's (1987) salutogenic theory, focusing on why people stay healthy. He defined SOC as a way one perceives the world–a person's expectation that he or she could make it through a difficult experience by drawing upon internal and external resources. Sense of coherence has three components: comprehensibility (making sense of a difficult event), manageability (able to cope with stressful situations), and meaningfulness (believing that life has a purpose). Controversy exists as to whether SOC is a state or a trait (Schnyder, Buchi, Sensky & Klaghofer, 2000). Antonovsky proposed that, although it may fluctuate at times as in the experience of cancer, SOC usually stabilizes in young adulthood and continues to develop over a lifetime.

Sense of coherence has been shown to correlate positively with QOL. In a study of 149 persons with coronary heart disease, Motzer and Stewart (1996) found that SOC had the highest correlation with QOL (r=.73), compared to 14 other predictors (e.g., gender, social support, and functional capacity). After controlling for the 14 other predictors, SOC resulted in a 15% increment to the explained variance in QOL (total R2 = .64). In a study of 42 persons with oral and pharyngeal cancer, patients with a strong SOC had significantly better psychosocial and physical functioning than those with moderate SOC (Langius, Bjorvell & Lind, 1994). In this study, it was hypothesized that SOC will correlate positively with QOL and explain a significant increment in QOL variance, after controlling for the other predictors.

Spouse and Dyadic Variables

Cancer profoundly affects not only the patient, but also close family members such as the spouse (Lewis, 1986; 1993). In seeking emotional support during the cancer experience, people lean on individuals who have supported them during difficult times in the past (Hill & Gallagher, 1996). Because of the longevity of many marriages in persons over 50 years of age, it is likely that the patient will rely on the spouse for support through the cancer experience. It is well documented that caregiving for someone with cancer is difficult (Given & Given, 1994; Stetz, 1987; Stetz & Brown, 1997). Family caregivers of persons with breast cancer report a wide range of emotions (e.g., fear, anger, and frustration), especially during the first year after diagnosis (Hilton, 1993). Primary in-home caregivers of persons with cancer reported emotional state changes–77% experienced anxiety, 81% felt fearful, 77% were unable to cope, 66% withdrew emotionally, and 75% reported sleep problems (Perry & de Meneses, 1989).

In this study, the majority of spouse caregivers (CG) were expected to be women because head and neck cancer is more prevalent in men (American Cancer Society, 1998; Vaughan et al, 1996). The spouse CG lives with and manages everyday problems created by the cancer and treatment at home. Mutuality and dyadic adjustment were chosen to measure qualities of the spousal relationship in this study. Mutuality pertains to the quality of the patient-spouse relationship in the context of caregiving. Dyadic adjustment refers to marital quality in general and was included in this study because it would allow comparison to normative data.

Mutuality. Mutuality is defined as "the positive quality of the relationship between a family caregiver and a care receiver (Archbold, Stewart, Greenlick & Harvath, 1992; p. 328). In a longitudinal study of 78 older caregiving dyads, mutuality explained 4 to 24% of the variance in aspects of caregiver role strain after controlling for 5 other predictors (Archbold, Stewart, Greenlick & Harvath, 1990). It was therefore hypothesized that higher levels of mutuality would be associated with more positive QOL for spouses in this study.

Dyadic adjustment. Dyadic adjustment is defined as "...a process, the outcome of which is determined by the degree of: (a) troublesome marital differences; (b) interpersonal tensions and personal anxiety; (c) marital satisfaction; (d) dyadic cohesion; and (e) consensus on matters of importance to marital functioning" (Spanier & Cole, p. 127). Married people typically report that the marital relationship is their main source of intimacy, support, and nurturing (Dunkell-Schetter, 1984). It was therefore expected that the quality of the spousal relationship would be positively associated with QOL.

A life-threatening illness such as cancer may precipitate a marital crisis (Peteet & Greenberg, 1995). However, in a study of 78 breast cancer patients and their spouses, marital satisfaction was reported by both groups to be higher than before diagnosis (Lichtman, Taylor & Wood, 1989). Fuller and Swenson (1992) assessed predictors of QOL in 42 married couples in which one individual had advanced cancer. For the patients, affiliation with their spouse was the best predictor of QOL (multiple $R = .44$; $p < .01$), while dyadic adjustment was the best predictor of QOL for spouses (multiple $R = 53$; $p < .001$).

Spouse Age, Gender, Depression, Stigma, and Sense of Coherence.

Quality of life of spouses was hypothesized to be associated with QOL in a manner similar to patients. Male gender, low depression, low stigma and high SOC were hypothesized to be related to a higher QOL.

Selection of Predictors

Predictors were selected based on the literature and on the observed experience of head and neck cancer patients and spouses. Justification for choice of variables has been provided in this literature review. Other commonly examined predictors of QOL are social support, self-esteem, and function. Social support was not used because it overlaps with dyadic adjustment. Self esteem is highly correlated (r=.5) with SOC (Motzer & Stewart, 1996). The disease-specific QOL outcome measure selected for this study includes aspects of function as its indicators. Smoking and alcohol use was not assessed to prevent the implication of blame.

Specific Aims and Related Hypotheses

The long term goal of this research is to improve the QOL of patients experiencing head and neck cancer and QOL of their spouses. The three major aims that guided this study were:

1. To describe the level and pattern of quality of life and stigma reported by head and neck cancer patients and by their spouses.
2. To examine the relative importance of illness-related, patient, and dyadic variables in explaining quality of life as an outcome for the head and neck cancer <u>patient</u>.

The hypothesis related to Aim 2 is that three sets of variables (illness-related, patient, and dyadic) will each contribute significantly to the explained variance in quality of life for the <u>patient</u>. Directional hypotheses for specific predictors were described earlier.

3. To examine the relative importance of illness-related, spouse, and dyadic variables in explaining quality of life as an outcome for the head and neck cancer <u>spouse</u>.

The hypothesis related to Aim 3 is that three sets of variables (illness-related, spouse, and dyadic) will each contribute significantly to the explained variance in quality of life for the <u>spouse</u>. Directional hypotheses for specific predictors were described earlier.

Chapter 3

Methods

Prior to implementing this study, a pilot study was conducted to evaluate the questionnaires in terms of their feasibility, readability and understandability with head and neck cancer patients and their spouses. In addition, feedback was requested to determine if the questionnaires were comprehensive in representing the head and neck cancer experience. A pilot sample of 6 head and neck cancer patients and 3 head and neck cancer spouses was recruited. Survey packets were mailed to the volunteers and were returned by mail. After evaluating the comments from these experts, it was determined that no changes in the questionnaires would be necessary. One patient and one spouse were included in the final study.

Design

For this study, a descriptive, correlational, cross-sectional design was used to describe the level and patterns of QOL reported by head and neck cancer patients and their spouses and examine the relative importance of illness-related, patient, spouse, and dyadic variables in explaining variations in QOL for patients and their spouses. Measures were obtained at one point in time during the first 6 years after initial surgery for head and neck cancer. Evans (1985) maintains that if measurement takes place at only one point in a patient's experience, the true picture of QOL may not emerge. We are not able to sequentially determine the changeability of QOL, or its "dynamism," as Allison, Locker and Feine (1997) refer to it. However, a cross-sectional design is appropriate for this study because it selects a representative sample from the population of interest at one point in time, allows for observation of the phenomenon of interest, and prevents adding to the burden of the participants (Mertens, 1998).

In a recent prospective study of 549 patients with head and neck cancer, Weymuller and colleagues (2000) reported numerous challenges to a longitudinal design with head and neck cancer patients. Some of those challenges included the expense, and participants not keeping their appointments and therefore not completing the surveys on time, filling out the surveys incompletely or wrong, and not returning the questionnaires.

Sample Criteria

Participants in this study included head and neck cancer patients and their spouses. After approval by the Institutional Review Boards of Oregon Health Sciences University (OHSU) and Legacy Health Systems (LHS), the Tumor Registries of these institutions created a list of cancer patients who met inclusion criteria: (a) 50 years of age or older; (b) currently married; (c) had stage II, III, or IV head or neck cancer at the time of diagnosis; and (d) had initial surgery within the past 6 years. Both patients and spouses had to be able to read and write English.

Sample Access Procedures

One hundred twenty-five patients met the inclusion criteria. A packet was sent to all eligible patients and their spouses containing (a) a cover letter explaining the study (Appendix A) addressed to the patient and his/her spouse, (b) a consent form (one for the patient and one for the spouse) (Appendix B), (c) a letter of support for the study from the physicians who performed the surgeries (Appendix C), and (d) a copy of the questionnaires--one for the patient and one for the spouse (Appendix D). The physician letter of support is a recruitment strategy that promotes trust and may increase responsiveness (Dillman, 1978).

One week after the initial mailing, a follow-up postcard was sent to patients and spouses reminding them of the importance of their participation (Appendix E). This is also an effective strategy to increase the response rate, according to Dillman (1978). All of the packets, postcards, and letters were hand-addressed–another strategy, suggested by Dillman, to personalize the correspondence and encourage participants' involvement in the study. For the completed surveys that were not received by 7 weeks, another set of questionnaires was sent. For those who returned the questionnaires, a letter of thanks was sent (Appendix F). Some of the participants sent short notes back stating that their spouse had died. Because there was no provision in the initial proposal to address these responses, a Project Amendment form was drafted and approval was granted by the Internal Review Board to send a letter of condolence and thanks for the 15 individuals who were included in this group.

Description of the Sample

The sample consisted of 33 patients who had undergone surgery for head and neck cancer, their 33 spouses, 7 patients who returned completed surveys whose spouses did not, and 7 spouses who returned completed surveys but the linked patients did not. Of the 125 packets that were mailed to eligible potential participants, 40 patients and 40 spouses responded. Table 1 displays a summary of responses to 125 mailed packets. Fifteen individuals sent back questionnaires with notations indicating that their spouse had died. For those individuals, a letter of condolence and thanks was sent. Fourteen surveys were returned, undelivered, indicating that there was no forwarding address. Two individuals sent their surveys back with notes stating that they were "too ill" and "too stressed" to complete the survey. Two individuals sent back their surveys indicating that the questions were “too personal.” One person was not included in the sample because he was divorced. The actual response rate for patients was 41.6%, excluding the 15 known deaths, 1 divorced person, and the 14 individuals known to have moved with no forwarding address. The response rate for spouses was also 41.6%.

The frequency distributions of demographic variables are displayed in Table 2. The average patient was fairly well-educated with partial college, retired, male, Caucasian, 70 years of age, had stage III at diagnosis, and had been diagnosed with head and neck cancer approximately 3 years prior to completing the survey. The typical spouse was a wife, also Caucasian (one spouse was Native American), 67 years of age, with partial college training. The couples had been married an average of 39 years; the median household income level was between $30,000 and $39,999.

Table 1

Summary of responses to 125 mailed packets.

Category	Number
Participants	
Both patient and spouse completed surveys	33 dyads
Only patient responded, spouse did not	7 patients
Only spouse responded, patient did not	7 spouses
Non respondents	
Returned with a note stating "too ill"	2 packets
Packet returned with a note stating the questions were "too personal"	2 packets
Packets not returned	45 packets
May have been eligible or not eligible	
Returned undelivered from post office	14 packets
Not eligible	
Packets returned with a note stating that one member of the dyad was deceased	15 packets
Survey was returned, completed, but dyad was divorced	1 survey

Response rate $= \dfrac{\text{Participants}}{\text{Participants + Nonrespondents}}$

Response rate for patients $= \dfrac{\text{33 (patients) + 7 (unlinked patients)}}{\text{33 (patients) + 7 (unlinked patients) + 7 (unlinked spouses) + 2 ("too ill")+ 2 ("too personal") + 45 (packets not returned)}}$

$= \dfrac{40}{96} = 41.6\%$

Response rate for spouses $= \dfrac{\text{33 (spouses) + 7 (unlinked spouses)}}{\text{33 (spouses) + 7 (unlinked patients) + 7 (unlinked spouses) + 2 ("too ill")+ 2 ("too personal") + 45 (packets not returned)}}$

$= \dfrac{40}{96} = 41.6\%$

Table 2

Frequency distribution of demographic variables (n=33 dyads, 7 patients without linked spouses, and 7 spouses without linked patients).

Variable	Mean (SD), Median, # and / or %	Range
Patients		
Age	68.8 years (9.9)	52-90 years
Gender	67.5% male	-
Race	100% Caucasian	-
Education	Junior high school: 1 (2.1%) Partial high school: 3 (6.4%) High school grad.: 13 (27.7%) Partial college: 13 (27.7%) Completed college: 7 (14.9%) Graduate professional: 3 (6.4%)	Junior high school to graduate professional training
Yearly household income	Not asked	-
Years married[a]	35.3 years (17.6)	3-62 years
Stage of disease for all 40 patients[a]	Stage II: 8 (17%)	II - IV
	Stage III: 15 (31.9%)	-
	Stage IV: 17 (36.2%)	-
Tumor site for all 40 patients[a]	Lip / Oral: 20 (50%)	-
	Pharynx: 9 (22.5%)	-
	Larynx / Glottis: 9 (22.5%)	-
	Parotid: 1 (2.5%)	-
	Sinus: 1 (2.5%)	-

Variable	Mean (SD), Median, # and / or %	Range
Spouses		
Age	67.6 years (10.4)	43-86 years
Gender	62.5% female	-
Race	39 (97%) Caucasian	-
	1 (2.5%) Native American	-
Education	Partial high school: 4 (10%)	-
	High school grad. 9 (22.5%)	-
	Partial college: 14 (35%)	-
	Completed college: 8 (20%)	-
	Graduate professional: 5 (12.5%)	-
Years married	35.4 years (19.6)	39-62 years
Yearly household income	Median income group: $30,000 - $39,000	$10,000-$19,000 to $100,000 or more
Stage of disease for all 40 spouses' patients[b]	Stage II: 8 (17%)	II - IV
	Stage III: 13 (27.7%)	-
	Stage IV: 19 (40.4%)	-
Tumor site for all 40 spouses' patients[b]	Lip / Oral: 21 (52.5%)	-
	Pharynx: 10 (25%)	-
	Larynx / Glottis: 7 (17.5%)	-
	Parotid: 1 (2.5%)	-
	Sinus: 1 (2.5%)	-

[a] These data are for the 40 patients who completed questionnaires.

[b] These data describe patient stage of disease and tumor site, obtained from the tumor registry, for the 40 spouses who completed questionnaires. For 7 of the 40 spouses, the patient did not return a questionnaire but tumor registry data were available.

Instruments

Each of the instruments selected for use in the study is described in this section. The instruments used to measure the predictor variables are discussed first, followed by the instruments used to measure the two dependent variables–QOL (global and disease-specific). Concepts to be measured, their definition, measures that were used, and psychometric characteristics are summarized in Table 3.

Table 3

Concepts, Definitions, Measures, and Their Characteristics.

Concept and Conceptual Definition	**Measure Name, Number of Items Response Format Example of Items**	**Meaning of Scores and Time to Complete**	**Source of data / Reliability (if applicable), Use in Specific Populations**
	Illness-Related Variables		
Disease Severity at Diagnosis	TNM staging system (determined by patient's surgeon prior to surgery)	Stages II, III, or IV	Data obtained from Tumor Registry records.
Time Since Initial Surgery	Length of time (in years) from date of first surgery to date survey was received	Within 6 years of start of study	Data obtained from Tumor Registry records.
Treatment Intensity	What type of treatment the patient is receiving or has received.	Surgery =1; Surgery plus radiation or chemo=2; surgery plus radiation plus chemo=3	Data obtained from Tumor Registry records.
Recurrence of Disease	Whether or not a patient has had a recurrence of H&N cancer since the initial surgery	Yes=1 No=0	Data obtained from Tumor Registry Records.

Concept and Conceptual Definition	Measure Name, Number of Items Response Format Example of Items	Meaning of Scores and Time to Complete	Source of data / Reliability (if applicable), Use in Specific Populations
	Patient and Spouse Variables		
Depression Self report of depressive symptomology (e. g., feelings of guilt, helplessness, or hopelessness).	Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977). A 20-item scale with a 0-3 response format. Sample items: [During the past week] "I was bothered by things that usually don't bother me." and "I felt depressed."	Higher scores indicate increased depression. Takes about 5 minutes to complete.	α=.85 for general population samples; .90 for a patient sample (Radloff, 1977). .85 for a community sample (n=235) and .91 for a clinical sample (n=88) (Himmelfarb & Murrell, 1983). .80 for frail elderly (Davidson, Feldman & Crawford, 1994). Low retest correlations (.32 to .67) (Radloff, 1977).
Stigma A feeling of disgrace by a person who has a condition or disease, coming from a fear of one's own vulnerability, uncertainty, or loss of control.	Stigma Inventory (Stahly, 1988) A 38-item scale with a Likert-type format from 1 (strongly agree) to 6 (strongly disagree). Sample items: "Since I have (my spouse has) been ill, some people seem to keep their distance from me (my spouse).	Higher scores reflect more perceived stigma. Takes about 20 minutes to complete.	No reliability data available. This measure has not been used with families. Written permission was granted by Stahly to use the tool, and to make revisions for use with the spouses.
Sense of Coherence A belief in one's ability to make it through difficult situations because he or she believes that there are reasons that make life worthwhile.	Sense of Coherence Scale (Antonovsky, 1993). A 29-item version with a 5-point Likert scale (1=very often; 5=never). Sample items: "How often do you have the feeling that there's little meaning in the things you do in your daily life?"	Higher scores reflect a stronger sense of coherence. Takes less than 5 minutes to complete.	α from .74 to .91 in 16 samples (Antonovsky, 1993). .87 in 149 persons surviving cardiac arrest, mean age 63.5 (Motzer & Stewart, 1996).
Mutuality The positive quality of the patient / caregiver relationship.	Mutuality Scale (Archbold, Stewart, Greenlick & Harvath, 1990). A 15-item scale with a 5-point response format from 0-4. Sample items: "To what extent do the two of you see eye to eye?" and "How often do you laugh together?"	Higher scores reflect greater perceived mutuality. Takes about 2 minutes to complete.	α=.91 at 6-week and 9-month interviews with 78 community-based, older family caregivers and care receivers (Archbold, Stewart, Greenlick & Harvath, 1990). .90 for 107 individuals recovering from cardiac surgery and .93 for their partners (Levine, 1993).

Concept and Conceptual Definition	Measure Name, Number of Items Response Format Example of Items	Meaning of Scores and Time to Complete	Source of data / Reliability (if applicable), Use in Specific Populations
Dyadic Adjustment A process determined by the degree of marital differences, interpersonal tensions, satisfaction, cohesion, and consensus.	Dyadic Adjustment Scale (Spanier, 1976). A 32-item scale. Likert-type, response format uses 5-, 6-, and 7-point response options. Two items require a dichotomous response of yes or no. Sample item: "In general, how often do you think that things between you and your partner are going well?"	Higher scores reflect better dyadic adjustment. Takes about 10 minutes to complete.	α=.96 with 218 married individuals (Spanier, 1976). Total scale alpha=.96; husbands=.87; wives=.93 (in 86 partners after cardiac arrest (Goodwin, 1995).
Quality of Life (Disease-Specific) A personal interpretation of one's well-being in the face of a specific disease (head and neck cancer).	University of Washington Quality of Life Questionnaire (Hassan & Weymuller, 1993). A 9-item scale with variable responses describing daily living limitations, disfigurement, and dysfunctions resulting from head and neck cancer surgery. Sample items: "I can't do anything enjoyable," and "I feel significantly disfigured and limit my activities due to my appearance."	Higher scores reflect better quality of life related to head and neck cancer. Takes less than 5 minutes to complete.	α >.90 in three phases. Shown to be sensitive to variability within and between stages of cancer (Hassan & Weymuller, 1993).
Quality of Life (Global) The degree of satisfaction with the perceived present life circumstances.	Modified Quality of Life Scale (Burckhardt, Woods, Schultz & Ziebarth, 1989). A 16-item version of Flanagan's (1982) QOLS using a 7-point Delighted (7) - Terrible (1) response option. Sample items: "Material comforts: home, food, financial security," and "Independence, being able to do things for yourself."	Higher scores reflect a better perceived quality of life. Takes less than 5 minutes to complete.	α=.86 to .92 over three time periods in 4 chronic illness groups; Test-retest reliabilities ranged from .76 for a 6-week interval to .78 and .84 for two 3-week intervals (Burckhardt, Woods, Schultz & Ziebarth, 1989). .91 in persons with chronic illness of coronary heart disease surviving cardiac arrest (Motzer & Stewart, 1996). .83 in group of 126 older patients with COPD (Anderson, 1995).

Predictors: Illness-Related Variables

Illness-related variables are disease severity at diagnosis (stage), time since initial surgery, treatment intensity, and recurrence of disease.

Disease severity at diagnosis (stage). The TNM (tumor, lymph node, metastasis) staging system is used prior to treatment to assess the extent of disease and design treatment options (American Joint Committee on Cancer, 1992). A stage is assigned by the surgeon based on data from the history, physical, and MRI. Staging takes into account tumor site, size (from T1 to T4), cervical lymph node involvement (N2 and N3 indicates that lymph nodes are involved), and metastasis (M1 indicates distant spread of the tumor). For this study, stage data were collected from LHS and OHSU Tumor Registry lists. The patients' stages of cancer ranged from II through stage IV.

Time since initial surgery. Tumor Registry lists were reviewed to determine the date of initial surgery, which was used to calculate the time since the initial surgery in years. The length of time began from the date of the initial surgery until the return of the questionnaire. For the patients, time in years ranged from 0.96 to 6.01 years (SD=1.61). For the spouses' patients, time ranged from 0.92 to 6.01 years (SD=1.64).

Treatment intensity. Tumor Registry lists were reviewed to determine the type of treatment each of the patients in the complete data set had received. For this study, a treatment intensity variable was created that determined if a patient had: surgery alone (1), surgery plus radiation / OR chemotherapy (2), and surgery plus radiation plus chemotherapy (3).

Recurrence of disease. For this study, the variable of recurrence of disease was dichotomous (yes=1; no=0) and indicated whether a patient's cancer had returned since the initial surgery. Two sources were used for recurrence data--Tumor Registry lists and one question asked at the end of the patient's questionnaire: "Has your cancer come back since the first surgery?" Because only 4 of the 40 patients reported recurrence of head and neck cancer, correlations of recurrence with other variables were not done, and the recurrence variable was not included in any of the analyses.

Predictor Variables: Patient and Spouse Characteristics

The variables included in "Patient and spouse characteristics" are depression, stigma and sense of coherence.

Depression. The Centers for Epidemiological Studies–Depression scale (CES-D) (Radloff, 1977) was used to measure depression in patients and spouses. The scale addresses affective components of depressed mood, psychomotor delay, loss of appetite, sleep disorders, and feelings of guilt, worthlessness, helplessness, and hopelessness. The CES-D has been used in many different populations including numerous age, racial, ethnic, and language groups (Radloff & Teri, 1986). Evidence for construct validity has been demonstrated by moderately high correlations with other established depression scales (Myers & Weissman, 1980; Radloff & Teri, 1986) and factor analysis (McDowell & Newell, 1996). Radloff and Teri report that the CES-D has good known-groups validity, and is also sensitive to detecting changes in depressive symptoms.

Stigma. The Stigma Inventory (Stahly, 1988) was used to measure perceived stigma in both patients and the spouses. The four domains within this concept include: (a) social presentation and social interaction. (b) victimization, self-blame, and superstition, (c) compliance and optimism, and (d) shame and secretiveness. To establish construct validity, factor analysis was done by Stahly but details were not published and are not currently available. The scale is relatively new and has not previously been used with head and neck cancer patients or their spouses.

Sense of coherence. The Sense of Coherence Scale (Antonovsky, 1987) was used to measure SOC. Sense of Coherence includes comprehensibility, manageability, and meaningfulness. Although studies have reported the use of the 3 subscales, one dominant factor for the scale has recently been explicated (Nesbitt & Heidrich, 2000). Content validity was assessed by a 4-member consensus panel that evaluated the appropriateness and categorization of each item. Evidence for construct validity has been demonstrated by: (a) known groups, (b) convergent validity, (c) discriminant validity, and (d) hypothesis testing.

Predictor Variables: Dyadic Variables

Mutuality. Mutuality includes love and affection, shared pleasurable activities, shared values, and reciprocity, and was measured with the Mutuality Scale developed by Archbold, Stewart, Greenlick and Harvath (1990). Evidence for construct validity was obtained in a longitudinal study of 78 older caregiving dyads in which mutuality was associated with lower levels of caregiver role strain, explaining 4 to 24% of the variance in seven measures of strain after controlling for five other predictors.

Dyadic adjustment. The Dyadic Adjustment Scale (DAS) (Spanier, 1976) is the second-most frequently used measure used in family research, reported from a database search of the years 1974 to 1997 (Piotrowski, 1999). The DAS contains 4 subscales: (a) dyadic satisfaction, (b) dyadic cohesion, (c) dyadic consensus, and (d) affectional expression. Evidence for content validity was provided by a panel of three judges. As evidence of construct validity, the DAS was positively correlated with an established marital adjustment scale (r=.86 among married respondents).

Dependent Variables: Patient and Spouse Quality of Life

Disease-specific quality of life measure for the patient only. The University of Washington Quality of Life Scale (UW-QOL) was developed by Hassan and Weymuller (1993) and was chosen because it captures the disease-specific issues that are unique to head and neck cancer patients. There are nine categories in the UW-QOL describing areas of daily living often affected by treatment of head and neck cancer (i.e., pain, disfigurement, chewing, swallowing, employment, speech, and shoulder disability). When correlated with another QOL measure for cancer, the UW-QOL scale demonstrated a criterion validity of .85.

Quality of life for the patient and the spouse. The QOL instrument by Flanagan (1982) was used to measure Global QOL. It was chosen because of its use in several different populations, including patients with chronic illness. The five domains in the QOL Scale (physical/material well-being, interpersonal relations, social, and community, activities, personal fulfillment, and recreation) were combined with independence as suggested by Burckhardt, Woods, Schultz and Ziebarth (1989). To assess construct validity of the Flanagan QOLS, Burckhardt and colleagues used three strategies: (a) high correlations with four other QOL measures; (b) known groups of stable ostomy patients were compared with unstable diabetes patients, and were shown to have significantly higher mean scores on the QOLS; and (c) high correlations with other instruments measuring the concept of health status.

Data Analysis

Returned questionnaires were reviewed for completeness. In the event of a pattern of missing data, Cohen and Cohen (1983) suggest that consideration be given regarding the specific factors that may have contributed to the missing data. If participants were missing an entire page or pages, the packet would have been mailed back to them with a short note stating that the pages must have gotten missed, and ask them to complete the form. No portions of any questionnaires needed to be returned to the participants for incompleteness.

Cohen and Cohen (1983) explain that it is common to have missing data in social and behavioral research. In relation to handling of missing data in this study, this rule was observed:

> Rule: if a subject was missing less than 25% of predictor items, the missing value was substituted with the group mean.

The group mean was entered for the responses on the global QOL Scale for 2 patients and 3 spouses because they had written "NA", indicating not applicable, in the margin or next to the item. The greatest amount of missing items for one individual on the QOL Scale was 7 items.

Regarding the predictors, the greatest amount of missing data from one individual came from a respondent who wrote on the questionnaire that the questions were too personal (on the Mutuality Scale and the DAS). In that particular case, the group mean was not entered. In another case where the group mean was not entered, a respondent left all of the items blank on the Dyadic Adjustment Scale, indicating "The pages I declined to answer I feel were questions which pertained to our marriage / relationship long before the surgery, or have no bearing on his speaking problem."

To maintain consistency in the direction of the responses at the item level, some of the items needed to be recoded, following the developers' instructions. Data were then checked for normality, skewness, and kurtosis. Data were also examined for outliers. Outliers were handled in the following manner: On the Quality of Life (Global) Scale, one spouse's score (3.10), more than 3 standard deviations lower than the mean, so it was "trimmed" to the next lowest score (4.25). Table 4 contains the descriptive statistics for each scale, including the mean, standard deviation, range, skewness and kurtosis.

Table 4

Descriptive Statistics for Continuous Variables.

Variables	**n**	**Missing**	**Possible range**	**Observed range**	**Mean (SD) or %**	**Skewness**	**Kurtosis**
Demographics							
Age							
Patient	40	0	50-100	52-90 years	68.8 (9.9)	.38	-.76
Spouse	40	0	unspecified	43-86 years	67.6 (10.4)	-.28	-.74
Gender				-			
(Female=1; Male=0)				-			
Patient	40	0	-		67.5% Male	-	-
Spouse	40	0	-		62.5% Female	-	-

Variables	n	Missing	Possible range	Observed range	Mean (SD) or %	Skewness	Kurtosis
<u>Illness-Related Variables</u>							
Disease Severity (stage)							
Patient[a]	40	0	II-IV	II-IV			
stage II					Stage II: 8 (17%)	-	-
stage II					Stage III: 15 (31.9%)	-	-
stage IV					Stage IV: 17 (36.2%)	-	-
Spouses' patients[b]	40	0		II-IV			
stage II					Stage II: 8 (17%)	-	-
stage II					Stage II: 13 (27.7%)	-	-
stage IV					Stage IV: 19 (40.4%)	-	-
Time Since Surgery							
Patient[a]	40	0	0-6 years	.96-6.01 years	3.09 (1.61)	.40	-1.26
Spouses' patients[b]	40	0	0-6 years	.92-6.01 years	3.34 years (1.64)	.17	-1.37

Variables	n	Missing	Possible range	Observed range	Mean (SD) or %	Skewness	Kurtosis
Treatment Intensity							
Patient[a]	40	0	1=surgery alone; 2=surgery plus radiation or chemotherapy; 3=surgery plus radiation plus chemotherapy	surgery alone; surgery plus radiation or chemotherapy; surgery plus radiation plus chemotherapy	Surg. alone: 21 (52.5%)	-	-
					Surg.plus radiation or chemo: 18 (45%)	-	-
					Surg. plus rad. plus chemo: 1 (2.5%)	-	-
Spouses' patients[b]	40	0	1=surgery alone; 2=surgery plus radiation or chemotherapy; 3=surgery plus radiation plus chemotherapy	surgery alone; surgery plus radiation or chemotherapy; surgery plus radiation plus chemotherapy	Surg. alone: 20 (50%)	-	-
					Surg. plus rad. or chemo: 18 (45%)	-	-
					Surg. plus rad. plus chemo: 2 (5%)	-	-

Variables	n	Missing	Possible range	Observed range	Mean (SD) or %	Skewness	Kurtosis
<u>Individual Variables</u>							
Depression							
(Total score)							
Patient	40	0	0-60	0-29	11.26 (7.48)	.76	-.20
Spouse	40	0	0-60	0-33	13.49 (8.96)	.38	-.22
Stigma (Mean item score)							
Patient	40	0	1.00-5.00	1.00-5.00	2.31 (.91)	.62	.33
Spouse	40	0	1.00-5.00	1.00-3.80	2.07 (.68)	.21	-.47
Sense of Coherence							
(Mean item score)							
Patient	40	0	1.00-7.00	3.83-6.21	5.14 (.70)	-.14	-1.28
Spouse	40	0	1.00-7.00	3.59-6.55	5.06 (.83)	-.06	-1.20

Variables	n	Missing	Possible range	Observed range	Mean (SD) or %	Skewness	Kurtosis
Dyadic Variables							
Mutuality							
(Mean item score)							
Patient	39	1	0.00-4.00	1.33-4.00	3.38 (.65)	-1.48	1.95
Spouse	40	0	0.00-4.00	1.00-4.00	3.13 (.74)	-1.10	1.12
Dyadic Adjustment							
(Total score)							
Patient	39	1	0-151	69.00-140.50	110.43 (16.65)	-.63	.14
Spouse	39	1	0-151	71.52-144.00	109.43 (17.63)	-.01	-.04
Dependent Variables							
Disease-Specific QOL							
(Total score)							
Patient only	40	0	0-800[c]	322.7-775.0	585.1 (118.2)	-.25	-.53
Global QOL							
(Mean item score)							
Patient	40	0	1.00-7.00	4.36-6.50	5.35 (.60)	.10	-.96
Spouse	40	0	1.00-7.00	4.31-6.62	5.38 (.62)	.07	-.74

[a] These data are for the 40 patients who completed questionnaires.

[b] These data describe patient stage of disease and tumor site, obtained from the tumor registry, for the 40 spouses who completed questionnaires. For 7 of the 40 spouses, the patient did not return a questionnaire but tumor registry data were available.

[c] Because the subscale of Employment was not used in this analysis, the possible scores range from 0-800 instead of 0-900 on the UW-QOL..

Internal consistency reliability for each of the scales in this sample was examined by determination of Cronbach's alpha. Table 5 displays the reliabilities for the measures. To compute the reliability, the missing data were first replaced by the mean of the item for this analysis. On the University of Washington Quality of Life Scale, the category of employment was removed because many (65%) of the patients in this sample were retired, and this item did not apply to them. With the item of employment removed, the reliability coefficient of the scale increased from .65 to .71. The reliability for all scales exceeded 70, the minimum recommended by Nunnally (1978) for use of a scale for research purposes.

This study used a descriptive, cross-sectional correlational approach to describe patterns of QOL in head and neck cancer patients and their spouses and to examine predictors of QOL. Measures were taken (mailed packets) at one point in time from patients who had surgery for head and neck cancer within the past 6 years and their spouses. Some modifications in the study occurred; a summary of the conceptual and design changes for the study and explanations of the modifications is in Appendix G.

Table 5

Reliabilities of Measures.

Scale	Patients' alpha	Spouses' alpha
CES-D	.83	.81
Stigma Inventory (Subscale 1: Social Presentation and Social Interaction)	.89	.77
Sense of Coherence Scale	.88	.93
Mutuality Scale	.96	.95
Dyadic Adjustment Scale	.93	.93
Quality of Life Scale (Disease-Specific)	.75	N/A
Quality of Life Scale (Global)	.91	.90

Chapter 4

Results

In this chapter, the results of data analysis are presented and summarized by the Aims of the study.

Aim 1. Describe the level and pattern of quality of life and stigma reported by head and neck cancer patients and by their spouses.

To determine the level and pattern of patient responses on the University of Washington QOL Scale, the means (and standard deviations), in order from high to low, were inspected. Refer to Table 6 for a summary of these responses. Forty to 55% of patients reported the best achievable score on 4 of 8 items. Three of these items related to pain, swallowing and shoulder disability, and represented the highest mean QOL in this sample. Although 47.5% of the patients reported the best achievable score in the area of chewing, the mean for that item was among the lowest, and the most variability in scores occurred with that item (SD=33.4). Patients reported disfigurement as being the area that represented the lowest QOL.

The frequency distributions for the UW-QOL Scale at the item level are presented in Figure 2.

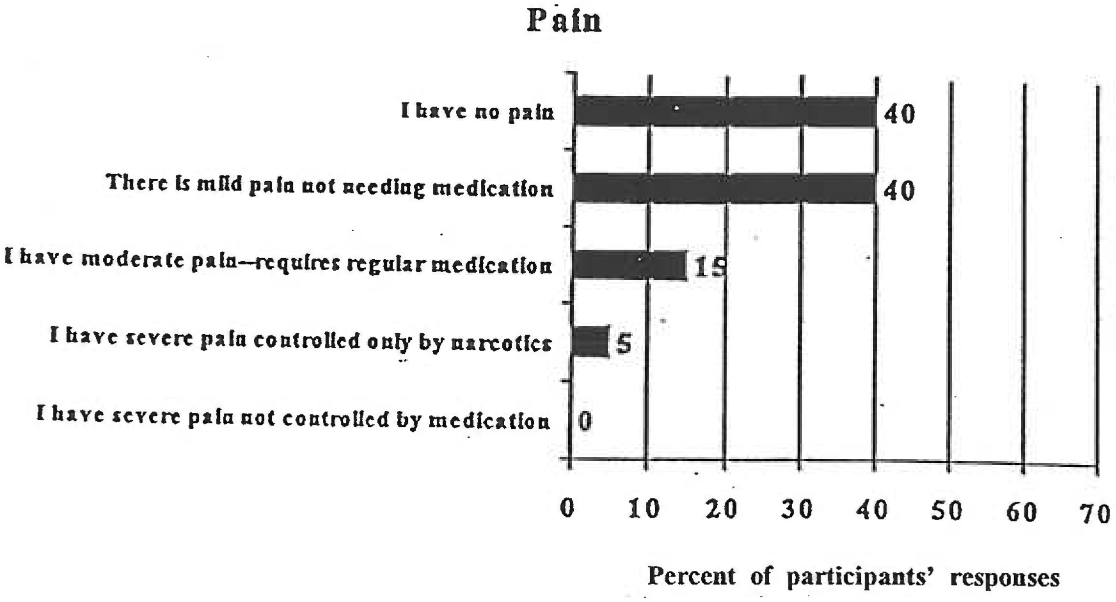
Table 6

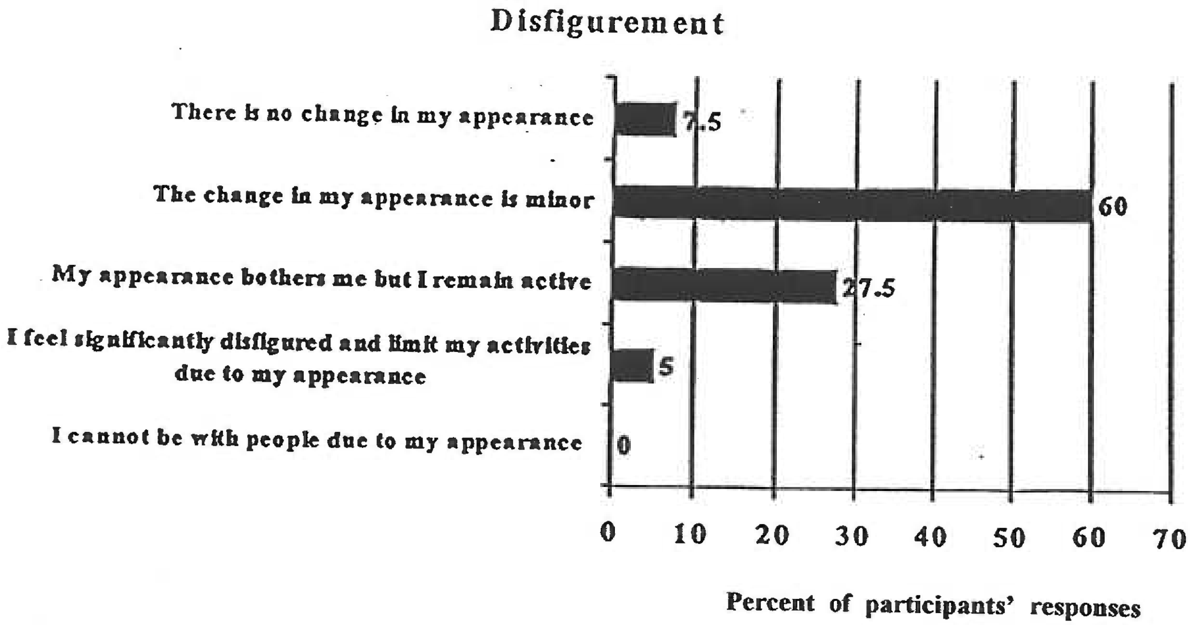
Patient Means on Disease-Specific Quality of Life Scale (The University of Washington Quality of Life Scale) Items in Descending Order (N=40).

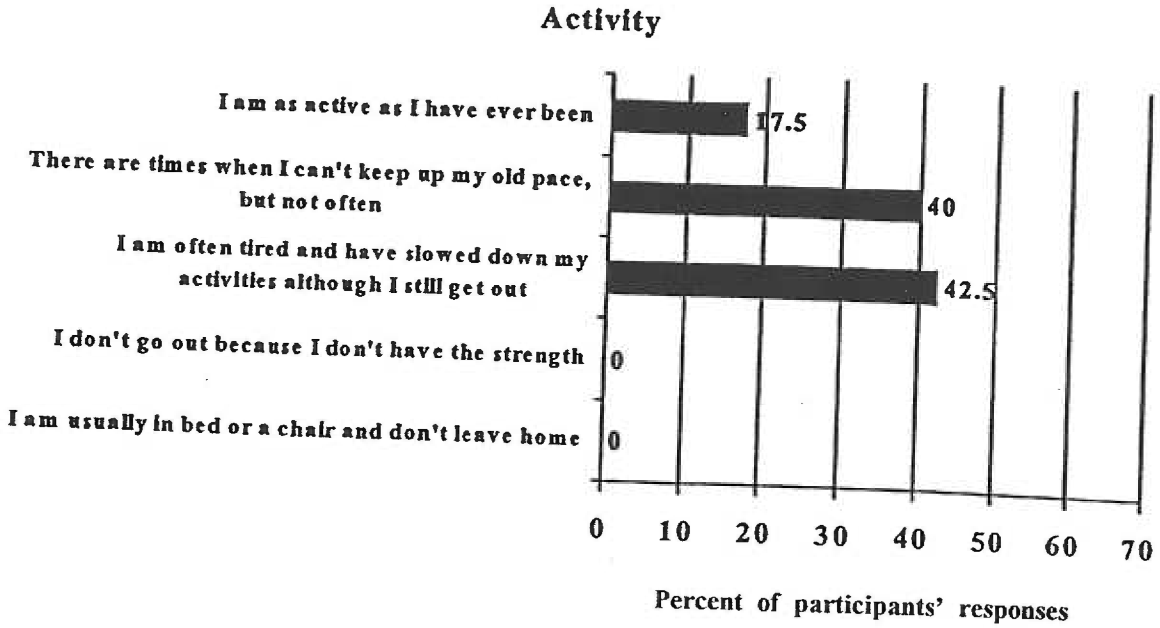
Subscale (Response range)	**Mean**	**SD**	**% Reporting best achievable score**
Pain (1 - 5)	78.8	21.6	40.0
Swallowing (1 - 4)	78.0	23.5	45.0
Shoulder disability (1 - 4)	76.6	31.0	55.0
Recreation / entertainment (1 - 5)	76.2	22.6	32.5
Speech (1 - 4)	70.5	24.0	27.5
Activity (1 - 5)	68.8	18.6	17.5
Chewing (1 - 3)	68.8	33.4	47.5
Disfigurement (1 - 5)	67.5	17.2	7.5

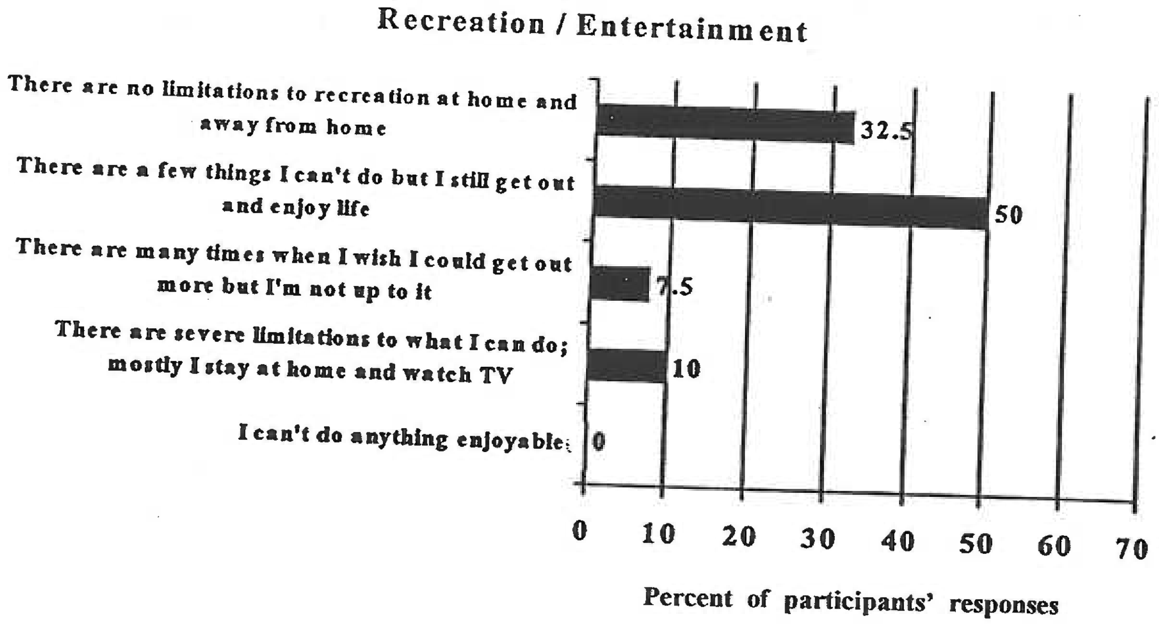
Note. Each subscale is rated on a 1 to 3, 1 to 4 or 1 to 5 scale and then transformed to a 0 to 100 scale. Higher scores indicate better QOL. The subscale of Employment was not included in the analysis.

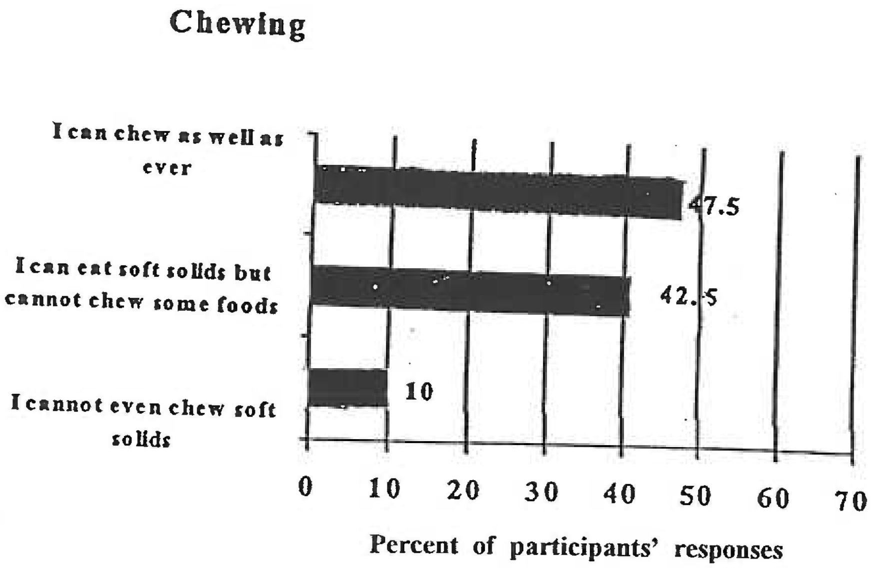
Figure 2. Frequency Distributions of Patient Responses at the Item Level on the UW-QOL Scale.

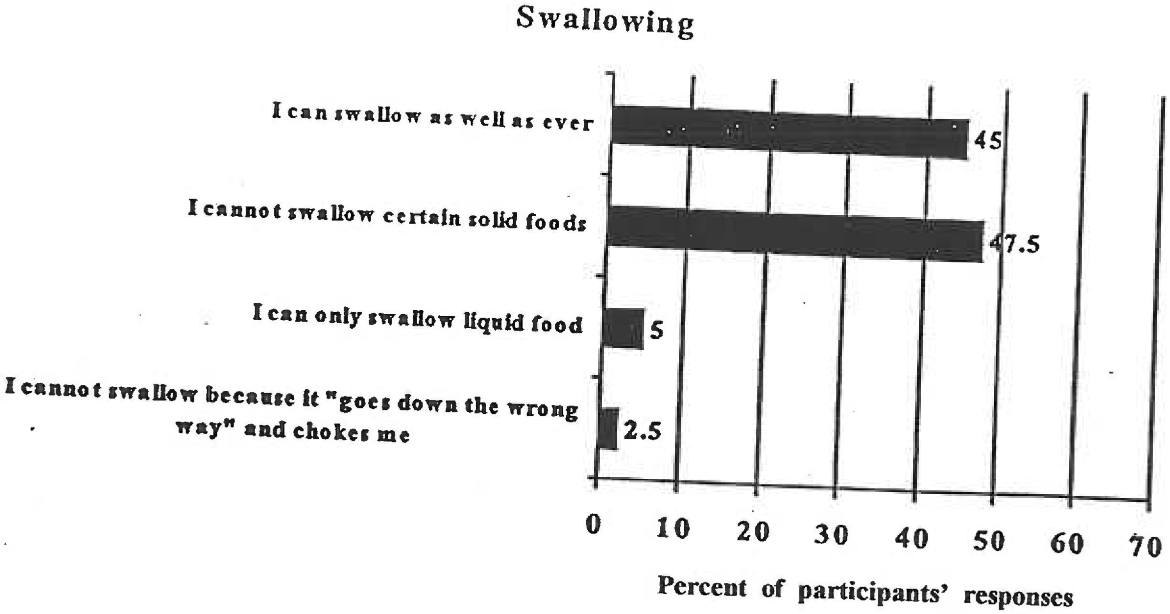


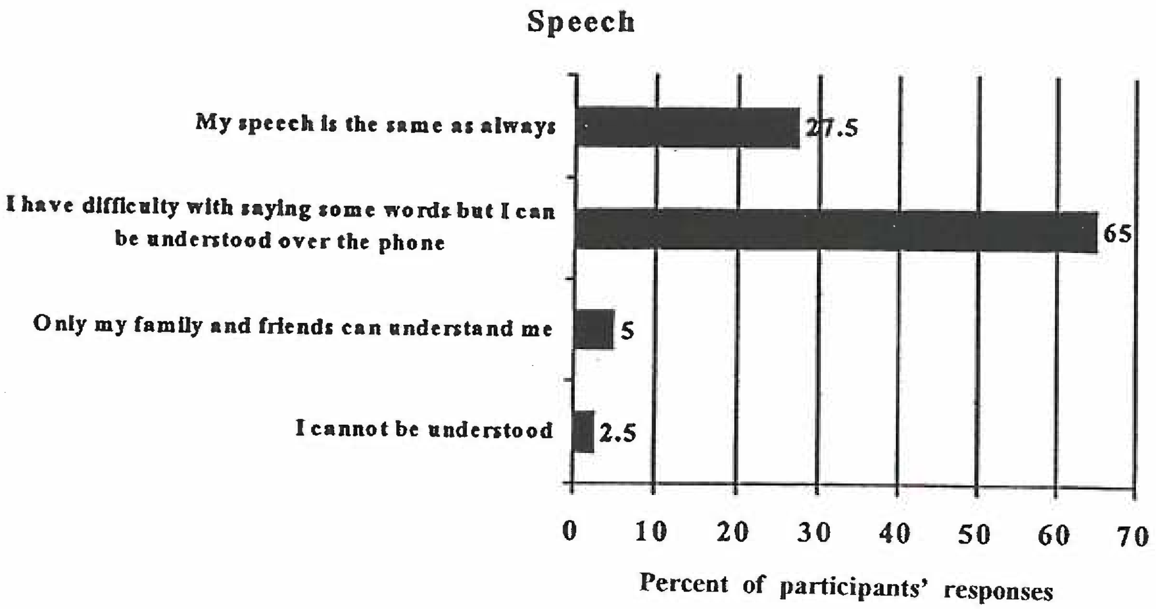


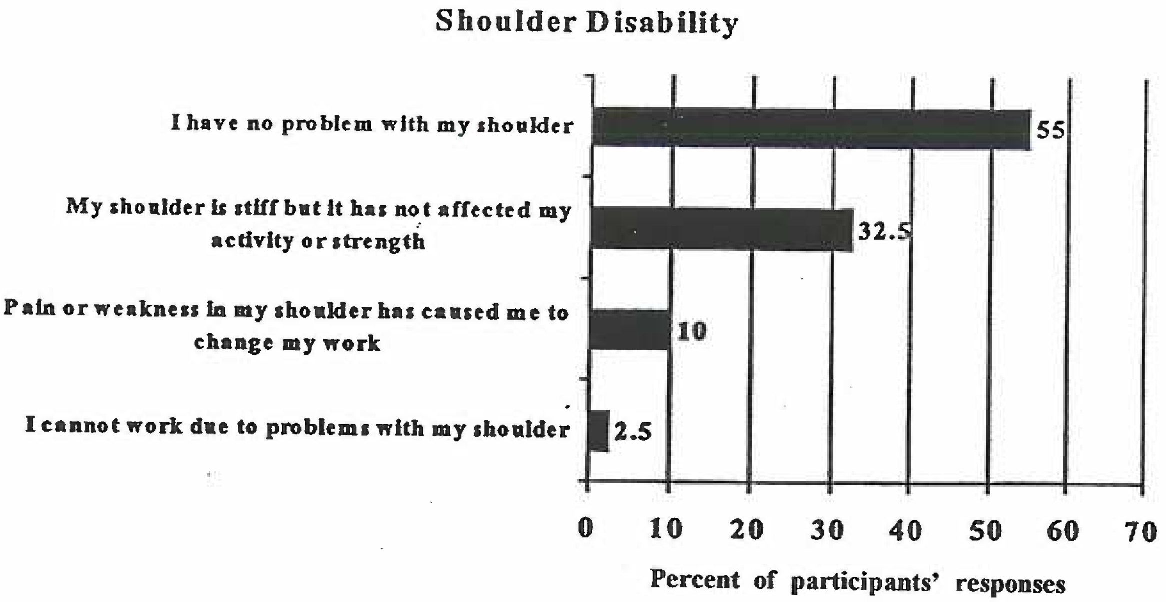

Activity
I am as active as I have ever been
17.5
There are times when I can't keep up my old pace, but not often
40
I am often tired and have slowed down my activities although I still get out
42.5
I don't go out because I don't have the strength
0
I am usually in bed or a chair and don't leave home
0
0
10
20
30
40
50
60
70
Percent of participants' responses


Recreation / Entertainment
There are no limitations to recreation at home and away from home
32.5
There are a few things I can't do but I still get out and enjoy life
50
There are many times when I wish I could get out more but I'm not up to it
7.5
There are severe limitations to what I can do; mostly I stay at home and watch TV
10
I can't do anything enjoyable
0
0
10
20
30
40
50
60
70
Percent of participants' responses


Chewing
I can chew as well as ever
I can eat soft solids but cannot chew some foods
I cannot even chew soft solids
47.5
42.5
10
0
10
20
30
40
50
60
70
Percent of participants' responses


Swallowing
I can swallow as well as ever
I cannot swallow certain solid foods
I can only swallow liquid food
I cannot swallow because it "goes down the wrong way" and chokes me
45
47.5
5
2.5
0
10
20
30
40
50
60
70
Percent of participants' responses


Speech
My speech is the same as always
27.5
I have difficulty with saying some words but I can be understood over the phone
65
Only my family and friends can understand me
5
I cannot be understood
2.5
0
10
20
30
40
50
60
70
Percent of participants' responses


Shoulder Disability
I have no problem with my shoulder
55
My shoulder is stiff but it has not affected my activity or strength
32.5
Pain or weakness in my shoulder has caused me to change my work
10
I cannot work due to problems with my shoulder
2.5
0
10
20
30
40
50
60
70
Percent of participants' responses

To determine the level and pattern of patient and spouse responses on the Global QOL Scale, the means (and standard deviations), in order from high to low, were inspected. Refer to Table 7 for a summary of these responses. In 10 of the 16 areas of QOL, 87% or more of the patients reported being mostly satisfied, pleased, or delighted. Patients ranked relationships with family and close friends, or activities that keep them close to home as the most satisfying. However, in 6 of the 16 areas, only 47% to 75% of patients reported being satisfied with the quality of their lives. These items include getting out and associating with individuals other than those close to them. The items with the greatest variability are those that involve participating in active recreation and health (being physically fit and vigorous).

Table 7

Patient Means on Global Quality of Life Scale Items in Descending Order (N=40).

Item	Mean	SD	% of Patients Mostly Satisfied, Pleased, Delighted
Close relations with spouse or significant other.	6.00	0.99	93
Reading, music, or watching entertainment.	5.80	0.91	90
Close friends.	5.67	0.68	100
Material comforts: home, food, financial security.	5.65	0.77	97
Relationships with parents, siblings & other relatives: communicating, visiting, helping.	5.64	0.86	90
Independence, being able to do things for yourself.	5.62	1.00	87
Having and rearing children.	5.62	0.58	97
Understanding yourself: knowing what life is about.	5.55	0.75	95
Learning: attending school, improving knowledge.	5.27	0.95	90
Work: Job or home.	5.26	0.68	90
Socializing: meeting other people, doing things.	5.20	0.99	75
Expressing yourself creatively.	5.10	0.95	75
Helping and encouraging others, volunteering.	5.00	0.88	72
Participating in active recreation.	4.79	1.34	65
Participating in organizations and public affairs.	4.75	0.98	72
Health: being physically fit and vigorous.	4.67	1.18	47

Note. Possible range: 1 (Terrible) to 7 (Delighted).

The items on the Global QOL Scale were also evaluated for the spouses. The level and pattern of their responses are detailed in Table 8. In 10 of the 16 areas of QOL, 82% or more of the spouses reported being satisfied. Spouses ranked having and rearing children as the most satisfying, followed by relationships with family and close friends, and then activities that keep them close to home. In 6 areas, only 47% to 72% of spouses were satisfied. These items include getting out and associating with individuals other than those close to them. There was somewhat more variability in the spouses' responses than in those of the patients'. The greatest variability for spouses was noted on items relating to participating in organizations, active recreation, and helping others and volunteering.

Table 8

Spouse Means on Global Quality of Life Scale Items in Descending Order (N=40).

Item	Mean	SD	% of Spouses Mostly Satisfied, Pleased, Delighted
Having and rearing children.	6.37	0.72	87
Close relations with spouse or significant other.	5.77	1.05	90
Reading, music, or watching entertainment.	5.75	0.84	92
Independence, being able to do things for yourself.	5.70	0.97	92
Relationships with parents, siblings & other relatives: communicating, visiting, helping.	5.63	1.05	82
Close friends.	5.63	1.09	87
Material comforts: home, food, financial security.	5.62	0.58	95
Understanding yourself: knowing what life is about.	5.55	1.11	90
Work: Job or home.	5.35	1.00	87
Expressing yourself creatively.	5.21	1.06	47
Socializing: meeting other people, doing things.	5.10	1.13	72
Learning: attending school, improving knowledge.	4.96	1.16	85
Helping and encouraging others, volunteering.	4.92	1.21	67
Health: being physically fit and vigorous.	4.89	1.17	70
Participating in active recreation.	4.73	1.23	62
Participating in organizations and public affairs.	4.60	1.38	65

Note. Possible range: 1 (Terrible) to 7 (Delighted).

To determine the level and pattern of patient responses on the Stigma Inventory, the means (and standard deviations), in order from high to low, were inspected. Refer to Table 9 for a summary of patients' responses on Subscales 1, 2, and 4. There is a distinction made between working and non-working patients on the item pertaining to being afraid that their illness may affect the way people judge their performance at work. Working patients reported higher stigma and than non-working patients, and 54% of working patients reported that they mildly to strongly agreed. Only 14% of non-working patients reported agreement on this item. On 6 of the 10 items on Subscale 1 (Social Presentation and Social Interaction), 20% to 40% of the patients reported agreement (mildly agree to strongly agree). These were in the areas of appearance, having to "break the ice" on social occasions, and sensing others' perceptions of the illness. On 4 of the 10 items, only 10% to 15% of the patients reported agreement in the areas of others treating them as though they were dying, wearing special clothes or makeup, and others' treating them as though the illness was contagious. Patients ranked items the highest that related to others judging them or others being embarrassed to ask about their illness. Higher scores on the scale indicate more perceived stigma.

On all 6 items on Subscale 2 (Victimization, Self-Blame and Superstition), only 3% to 5% of the patients reported agreement. They ranked highest those items pertaining to their feeling that others blamed them for their illness and their belief that it is bad luck to talk about illness. On 3 of the 6 items on Subscale 4 (Shame and Secretiveness), 13% to 38% of patients reported agreement in the areas of discussing the illness. On 2 of the 6 items, only 5% to 8% of the patients reported agreement in areas of being ashamed to discuss the illness, and wanting to ask their doctor questions but were reluctant. They ranked highest those items pertaining to thinking some aspects of a serious illness are best not discussed, wanting to see their doctor alone to ask questions that might upset their spouse, and feeling comfortable discussing their illness with close friends. Subscales 2 and 4 were not used in the analysis for patients or for the spouses, but are presented in the table because some of the items are consistent with Goffman's (1963) discussions of stigmatized individuals.

Table 9

Patient Means for Stigma Inventory Items on 3 Subscales–Each in Descending Order.

Item	**Mean**	**SD**	**% Mildly agree, Strongly agree**
Subscale 1: Social Presentation and Social Interaction			
All patients: I am afraid my illness may affect the way people judge my performance at work.	2.90	1.28	25
Working patients: I am afraid my illness may affect the way people judge my performance at work.	3.00	1.67	54
Non-working patients: I am afraid my illness may affect the way people judge my performance at work.	2.87	1.13	14
I think a lot about my appearance since I've been ill.	2.85	1.51	42
I sense others are sometimes embarrassed to ask about my illness.	2.72	1.30	30
People don't seem to know quite how to react to me since I've been ill.	2.49	1.26	20
Since my illness I find I must often "break the ice" on social occasions to put others at ease.	2.47	1.34	30
I think people often hide their feelings from me.	2.30	1.11	15
Since I've been ill some people seem to keep their distance from me.	2.05	1.34	20
Some people treat me as if my illness were contagious.	1.82	1.30	15
Although my chances of recovery are good, some friends treat me as if I were dying.	1.79	1.20	10
I wear special clothes and/or makeup so the effects of the illness won't be noticed by others.	1.72	1.22	15

Item	Mean	SD	% Mildly agree, Strongly agree
Subscale 2: Victimization, Self-Blame and Superstition			
I sometimes feel others blame me for my illness.	2.12	1.47	5
Some people I know seem to believe it's bad luck to talk about illness.	1.85	1.44	3
I am embarrassed by my illness.	1.67	1.18	5
I worry that my illness may be contagious.	1.50	1.18	5
Some people seem to feel that if they think too much about my illness they may get it too.	1.45	0.87	3
Talking about serious illness may be tempting fate.	1.27	0.85	5
Subscale 4: Shame and Secretiveness			
I think some aspects of a serious illness are best not discussed.	2.72	1.45	38
I would like to see my doctor alone sometimes so I can ask questions that might upset my spouse.	1.95	1.32	18
I feel comfortable discussing my illness with close friends (reverse coded).	1.67	0.92	12
There are some aspects of my illness that I really can't discuss with anyone.	1.60	1.24	13
I am ashamed to discuss my illness.	1.50	1.13	5
There are questions I would like to ask my doctor but I am reluctant to ask.	1.47	1.13	8

Note. Possible response range: 1 (Strongly Disagree) to 5 (Strongly Agree); Observed range on all items: 1 - 5, with 5 representing more stigma.

The levels and patterns of responses were also evaluated for the spouses. Refer to Table 10 for a summary of these responses. There is also a distinction made between working and non-working spouses' patients on the item pertaining to being afraid that the illness may affect the way people judge the patient's performance at work. Spouses of working patients reported higher stigma than spouses of non-working patients, and 33% of spouses of working patients reported agreement (mildly agree to strongly agree) on this item. Only 8% of the spouses of non-working patients reported agreement on this item. On 3 of the 10 items on Subscale 1, 25% to 32% of the spouses reported agreement in the areas relating to sensing that others are embarrassed to ask about the patient's illness, that others don't know how to react, and that they (spouses) needed to "break the ice" on social occasions. On 7 of the 10 items, only 5% to 17% of spouses reported agreement in the areas of others' treating the illness as though it was contagious or treating them (the patient and spouse) as though the patient was dying.

On 4 of the 6 items on Subscale 2 (Victimization, Self-Blame and Superstition), only 3% to 5% of the spouses reported agreement in areas of feeling that others' blamed the patient for the illness, being embarrassed about the illness, or that the illness may be contagious. They ranked all 6 items as being fairly low on their perception of stigma.

On 4 of the 6 items on Subscale 4 (Shame and Secretiveness), 22% to 30% of spouses reported agreement in the areas of wanting to see the doctor alone to ask questions that might upset the patient, feeling that some aspects of the illness are best not discussed or could not be discussed with anyone, and being reluctant to ask the doctor questions. On 1 of the 6 items, only 3%% of the spouses reported agreement in the area of being ashamed to discuss the illness. They ranked highest those items pertaining to wanting to see their doctor alone to ask questions that might upset their spouse, not being able to discuss some aspects of the illness with anyone, and believing that some aspects of a serious illness are best not discussed.

Table 10

Spouse Means for Stigma Inventory Items on 3 Subscales–Each in Descending Order.

Item	Mean	SD	% Mildly agree, Strongly agree
Subscale 1: Social Presentation and Social Interaction			
I sense others are embarrassed to ask about my spouse's illness.	2.69	1.24	32
People don't seem to know quite how to react to my spouse since he or she has been ill.	2.60	1.26	27
I think people often hide their feelings from my spouse and me.	2.52	1.20	17
Since my spouse's illness I find I must often "break the ice" on social occasions to put others at ease.	2.20	1.40	25
All spouses: I am afraid my spouse's illness may affect the way people judge his or her performance at work.	2.00	1.01	17
Spouses of working patients: I am afraid my spouse's illness may affect the way people judge his or her performance at work.	2.99	1.67	33
Spouses of non-working patients: I am afraid my spouse's illness may affect the way people judge his or her performance at work.	1.83	0.87	8
Since my spouse has been ill some people seem to keep their distance from him or her.	1.97	1.27	17
I think a lot about my spouse's appearance since he or she has been ill.	1.80	1.22	12
Although my spouse's chances of recovery are good, some friends treat us as if he or she were dying.	1.70	1.09	5
My spouse wears special clothes and/or makeup so the effects of the illness won't be noticed by others.	1.69	1.15	15

Item	Mean	SD	% Mildly agree, Strongly agree
Some people treat us as if my spouse's illness were contagious.	1.50	.93	5
Subscale 2: Victimization, Self-Blame and Superstition			
I sometimes feel others blame my spouse for his or her illness.	1.97	1.29	3
Some people I know seem to believe it's bad luck to talk about illness.	1.42	0.84	5
I worry that my spouse's illness may be contagious.	1.26	0.84	5
I am embarrassed by my spouse's illness.	1.17	0.59	3
Some people seem to feel that if they think too much about my spouse's illness they may get it too.	1.17	0.55	0
Talking about serious illness may be tempting fate.	1.12	0.46	0
Subscale 4: Shame and Secretiveness			
I would like to see my spouse's doctor alone sometimes so I can ask questions that might upset my spouse.	2.30	1.54	30
There are some aspects of my spouse's illness that I really can't discuss with anyone.	2.22	1.48	27
I think some aspects of a serious illness are best not discussed.	2.17	1.24	25
There are questions I would like to ask my spouse's doctor but I am reluctant to ask.	1.92	1.35	22
I feel comfortable discussing my spouse's illness with close friends (reverse coded).	1.80	1.11	12
I am ashamed to discuss my spouse's illness.	1.22	0.73	3

Note. Possible response range: 1 (Strongly Disagree) - 5 (Strongly Agree); Observed range on all items: 1 - 5, with 5 representing more stigma.

Aim 2. Examine the relative importance of illness-related, patient, and dyadic variables in explaining quality of life as an outcome for the head and neck cancer patient.

Quantitative data from self-report questionnaires were analyzed using Pearson's product moment correlation. Refer to Table 11 for a summary of the patients' bivariate Pearson's correlations of the predictors of QOL with the dependent variables. Correlation matrices of all patient predictor variables in the analysis are in Table 12. Pearson's r correlation designates the magnitude and direction of a relationship between two variables (Polit, 1996). An assumption in using correlation coefficients is that the relationship between a predictor and an outcome variable, or criterion, is linear (Pedhazur & Schmelkin, 1991). For example, using a predictor of mutuality, one may predict that the better quality of relationship of the couple, the better quality of life each of them may perceive.

Table 11

Predictors of Patient Quality of Life: Bivariate Pearson Correlations.[a]

Predictors	Dependent Variables Patient Quality of Life (Disease-Specific)	Patient Quality of Life Global)
Demographic Variables		
Age (Years)	-.21	-.03
Gender (Female=1; Male=0)	.14	.40*
Illness-Related Variables		
Stage [b]	-.02	.07
Time Since Surgery	.18	-.03
Treatment Intensity[c]	-.26	-.17
Individual Variables		
UW-QOL	-	.52*
Depression	-.45††	-.42††
Stigma	-.31†	-.31†
Sense of Coherence	.23	.50††
Dyadic Variables		
Mutuality	-.22	-.001
Dyadic Adjustment	-.09	.11

[a] These data are for the 40 patients who completed questionnaires.

[b] Stage: II, III or IV.

[c] Treatment intensity: 1=surgery only; 2=surgery plus radiation OR chemotherapy; 3=surgery plus radiation plus chemotherapy.

*p<.05; **p<.01; 2 tailed

†p<.05; ††p<.01; 1-tailed

Table 12

Correlation Matrix for Patient Predictor Variables (n=40).[a]

	1	2	3	4	5	6	7	8	9	10
1. Age (Yrs)		-.05	-.19	.15	-.07	.24	.07	.13	.18	.22
2. Gender (F=1; M=0)			-.28	.04	-.24	-.04	.06	.23	-.28	-.06
3. Stage [a,b]				-.34*	.21	-.31*	-.27	.13	.16	.00
4. Time Since Surgery (Yrs)[a]					-.28	.29	.37*	-.11	-.37*	-.41*
5. Treatment Intensity [a,c]						-.04	.27	-.13	.26	.32*
6. CES-D							.49**	-.52**	-.09	-.25
7. Stigma								-.38*	-.14	-.08
8. SOC									.14	.31
9. Mutuality										.77**
10. Dyadic Adjustment										

[a] These data are for the 40 patients who completed questionnaires.

[b] Stage: II, III or IV.

[c] Treatment intensity: 1=surgery only; 2=surgery plus radiation OR chemotherapy; 3=surgery plus radiation plus chemotherapy.

*p<.05; **p<.01; 2-tailed.

Patient Demographic Variables

The demographic variables included patients' age and gender. There was no association between patient age and QOL (global or disease-specific). The association between gender and global QOL was postive, with female patients reporting higher QOL (r=.40, p=.010). No association was found between gender and disease-specific QOL.

Patient Illness-related Variables

Illness-related variables include disease severity at diagnosis (stage), time since initial surgery, and treatment intensity. None of the associations between illness-related variables–stage, time since initial surgery, or treatment intensity and patients' global QOL and disease-specific QOL was significant.

Patient Characteristics

Patient characteristics include depression, stigma, and sense of coherence.

Depression. The association between depression, as measured by the CES-D, and global QOL for patients was negative (r=-.42; p=.007). Persons who report higher levels of depression also report lower levels of QOL. The same was true for patients' depression and disease-specific QOL (r=-.45; p=.003). Higher levels of patients' depression were associated with lower levels of physical functioning after surgery for head and neck cancer.

On the CES-D, 22% of the patients scored 16 or above. A score of 16 is usually considered to be indicative of clinical depression (Radloff, 1977).

Stigma. There was a negative association between patients' perceived stigma and disease-specific QOL (r=-.31; p=.050). Patients with higher levels of stigma reported lower QOL on the UW-QOL Scale. Although there was a negative association between patients' stigma and global QOL (r=-.31), the relationship was not significant.

Sense of coherence. A positive correlation was found between SOC and global QOL with the patients (r=.50; p=.001), but the association between SOC and disease-specific QOL for patients (r=.23) was not significant.

Patient Dyadic Variables

Mutuality and Dyadic Adjustment are the two dyadic variables.

Mutuality. Pearson correlation analysis revealed no significant correlation between mutuality and global QOL (r=-.001), or disease-specific QOL (r=-.22) for the patients.

Dyadic adjustment. Although the Pearson r correlation between dyadic adjustment and global QOL was .11, this relationship was not significant. No relationship was found between dyadic adjustment and disease-specific QOL for patients (r=-.09).

Major Findings for Aim 2

The main findings related to Aim 2 were that, of the demographic variables and illness-related variables, only patient female gender was associated with higher global QOL. There were no other significant correlations with global or disease-specific QOL with head and neck cancer patients. Depression was moderately correlated with both global and disease-specific QOL. Sense of coherence was associated with patients' global QOL, but not with disease-specific QOL. The dyadic variables (mutuality and dyadic adjustment) were not associated with QOL for the patients.

Hierarchical multiple regression was used for the analysis to determine which factors contribute significantly to the explained variance in outcome variable (Tabachnick & Fidell, 2001). The predictor variables were first entered into the regression individually. To determine how much a particular variable contributes to the explained variance in QOL, the R^2 increment was evaluated, along with the F change values relating to the R^2 change. The relative contributions of the IVs were examined the by looking at the significant beta weights and by observing the signs (+ or -).

Table 13 shows patient QOL regression with the UW-QOL Scale as the dependent variable. A hierarchical approach was used, and the logic of the order of entry of the variables is as follows. Illness-related variables and demographic variables were entered first because they are items that cannot be altered. They are therefore controlled for in the analysis. Stigma was then entered so that its effects may be controlled for in evaluating the increment of variance that may be explained by depression, SOC, and then the dyadic variables.

At entry, the standardized betas (β) revealed that depression carried the heaviest amount of weight (β=-.45), which implies that, for every 1 standard deviation rise in depression, patient UW-QOL declines by .45 SD units of measurement. Stigma carried the next highest weignt (β=-.42), followed by age (β=-.27), and treatment intensity (β=-.23).

In examining the R^2 change values, it was determined that depression added the greatest amount, 13.3%, to the explained variance in UW-QOL after controlling for the previously entered predictors ($p<.05$). Stigma accounted for an increment of 11.4% of the variance in patient UW-QOL.

Table 13

Predictors of Patient Disease-Specific Quality of Life (UW-QOL Scale[a]): Multiple Regression Summary (N=39).

Step	Variable	β weight at entry	R^2 Change	R^2	Adj R^2
1.	Stage[b]	-.013	.000	.000	-.027
2.	Years Since Surgery	.154	.021	.021	-.033
3.	Treatment Intensity[c]	-.229	.049	.070	-.010
4.	Age	-.271	.071	.140	.039
5.	Gender[d]	.106	.010	.150	.021
6.	Stigma	-.418*	.114*	.264	.125
7.	Depression	-.449*	.133*	.396*	.260
8.	Sense of Coherence	-.097	.005	.402*	.242
9.	Mutuality	-.097	.007	.409*	.225
10.	Dyadic Adjustment	.189	.009	.417	.209

Note. Adj = Adjusted.

[a] UW-QOL Scale = The University of Washington Quality of Life Scale (Hassan & Weymuller, 1993).

[b] Stage: II, III or IV.

[c] Treatment intensity: 1=surgery only; 2=surgery plus radiation OR chemotherapy; 3=surgery plus radiation plus chemotherapy.

[d] Gender: 0 = Male, 1 = Female.

*$p<.05$

Correlations among the predictors were examined, as well as the correlations of the predictors with the dependent variables. Tabachnick and Fidell (2001) explain that "regression is best when each IV is strongly correlated with the DV but uncorrelated with each other" (p.116). The unique contributions of each predictor (beta weights) were also examined, along with the R^2 increment values and the F change values. Taking each of these issues into account, and in view of the small sample size, it was determined that a more parsimonious model would be sought. The following rule was observed for selection of the predictors to be used in this new model: To be considered for inclusion in the more parsimonious model, a predictor must possess a Pearson's r correlation with the dependent variable of .3 or greater and must explain an additional increment of 4% or more. This rule was observed for each of the more parsimonious models to be presented.

Table 14 displays a more parsimonious model for predictors of patient disease-specific QOL. At entry, the standardized betas (β) revealed that depression carried the heaviest amount of weight (β=-.43), which implies that, for every 1 standard deviation rise in depression, patient UW-QOL declines by .43 SD units of measurement. Treatment intensity carried the next highest weight (β=-.26), followed by stigma (β=-.24), and finally age (β=-.22). In examining the R^2 change values, it was determined that depression added the greatest amount (12.5%) to the explained variance in UW-QOL after controlling for the previously entered predictors ($p<.05$). Treatment intensity accounted for 6.8% of the explained variance in disease-specific QOL.

Table 14

Predictors of Patient Disease-Specific Quality of Life (UW-QOL Scale[a]):

Multiple Regression Summary--A More Parsimonious Model(N=40).

Step	Variable	β weight at entry	R^2 Change	R^2	Adj R^2
1.	Treatment Intensity [b]	-.261	.068	.068	.044
2.	Age	-.225	.050	.119	.071
3.	Stigma	-.241	.053	.172	.103
4.	Depression	-.426*	.125*	.297†	.216

[a] UW-QOL Scale = The University of Washington Quality of Life Scale (Hassan & Weymuller, 1993).

[b] Treatment intensity: 1=surgery only; 2=surgery plus radiation or chemotherapy; 3=surgery plus radiation plus chemotherapy.

*p<.05

†p<.05; ††p<.01; 1-tailed

Table 15 displays a summary of patient global QOL multiple regression. Using Global QOL as the dependent variable, the variables were entered into the regression analysis individually. The logic underlying the order of entry of the predictors was as follows. The illness-related variables and demographics are items that cannot usually be altered, so they are controlled for in the analysis. It was determined that the UW-QOL Scale would be used as a predictor. It was entered next to control for the functional difficulties that, according to the literature, many patients have reported. Then, the individual characteristics, such as perceived stigma, depression and SOC were entered. Finally, the dyadic variables were entered to determine how much variance may be explained in QOL by the marital relationship, after controlling for all other predictors. At entry, the standardized betas (β) revealed that the UW-QOL scale carried the heaviest amount of weight (β=.55), followed by female gender (β=.43), then SOC (β=.33).

The R^2 change values were examined to determine what % of additional variance was contributed by a predictor after controlling for all others. Again, the UW-QOL scale added the greatest amount, 25.7%, to the explained variance in QOL after controlling for the previously entered predictors ($p<.05$). Gender accounted for an increment of 16% of the variance in patient global QOL and SOC added 6.1%.

Table 15

Predictors of Patient Global Quality of Life: Multiple Regression Summary (N=39).

Step	Variable	β weight at entry	R^2 Change	R^2	Adj R^2
1.	Stage[a]	.067	.005	.005	-.022
2.	Years Since Surgery	.015	.000	.005	-.051
3.	Treatment Intensity[b]	-.212	.042	.046	-.035
4.	Age	.005	.000	.046	-.066
5.	Gender[c]	.430*	.160*	.206	.086
6.	UW-QOL[d]	.549*	.257*	.463*	.362
7.	Stigma	-.174	.017	.480*	.362
8.	Depression	-.141	.011	.490*	.354
9.	Sense of Coherence	.327	.061	.551*	.412
10.	Mutuality	.124	.011	.562*	.406
11.	Dyadic Adjustment	-.093	.002	.564*	.387

Note. Adj = Adjusted.

[a] Stage: II, III or IV.

[b] Treatment intensity: 1=surgery only; 2=surgery plus radiation OR chemotherapy; 3=surgery plus radiation plus chemotherapy.

[c] Gender: 0 = Male, 1 = Female.

[d] UW-QOL Scale = The University of Washington Quality of Life Scale (Hassan & Weymuller, 1993).

*$p<.05$

Table 16 displays a more parsimonious model for predictors of patient global QOL, using the UW-QOL Scale as one of the predictors. At entry, the standardized betas (β) revealed that UW-QOL carried the heaviest amount of weight (β=.49), which implies that, for every 1 standard deviation rise in UW-QOL, patient global QOL increases by .49 SD units of measurement. Gender carried the next highest weight (β=.38), indicating that female patients have a higher global QOL, followed by stigma (β=-.22), and finally treatment intensity (β=-.17). In examining the R^2 change values, it was determined that UW-QOL added the greatest amount (22.1%) to the explained variance in UW-QOL after controlling for treatment intensity and gender. Gender accounted for 13.8% of the explained variance in global QOL after controlling for treatment intensity.

Table 16

Predictors of Patient Global Quality of Life: Multiple Regression Summary–A More Parsimonious Model (N=40).

Step	Variable	β weight at entry	R^2 Change	R^2	Adj R^2
1.	Treatment Intensity[a]	-.170	.029	.029	.003
2.	Gender[b]	.383*	.138*	.167*	.122
3.	UW-QOL[c]	.488*	.221†	.388*	.337
4.	Stigma	-.219	.040	.428*	.363

[a] Treatment intensity: 1=surgery only; 2=surgery plus radiation or chemotherapy; 3=surgery plus radiation plus chemotherapy.

[b] Gender: 0 = Male, 1 = Female.

[c] UW-QOL Scale = The University of Washington Quality of Life Scale (Hassan & Weymuller, 1993).

*$p<.05$, **$p<.01$; 2-tailed

†$p<.05$; ††$p<.01$; 1-tailed

Aim 3. Examine the relative importance of illness-related, spouse, and dyadic variables in explaining quality of life as an outcome for the spouse.

Quantitative data from spouses' self-report questionnaires were also analyzed using Pearson's product moment correlation. Refer to Table 17 for a summary of the spouses' bivariate Pearson's correlations of the predictors of QOL with the dependent variables. Correlation matrices of all spouse predictor variables in the analysis are in Table 18.

Table 17

Predictors of Spouse Quality of Life: Bivariate Pearson Correlations (N=40).

Predictors	Dependent Variable Spouse Quality of Life (Global)
Demographic Variables	
Age (Years)	.07
Gender (Female=1; Male=0)	-.01
Illness-Related Variables[a]	
Stage [b]	-.17
Time Since Surgery	-.19
Treatment Intensity[c]	-.18
Individual Variables	
Depression	-.53[††]
Stigma	-.25
Sense of Coherence	.57[††]
Dyadic Variables	
Mutuality	.46[†]
Dyadic Adjustment	.53[††]

[a] These data describe the type of patient treatment for the 40 spouses who completed questionnaires. For 7 of the spouses, the patient did not return a questionnaire but had tumor registry data available.

[b] Stage: II, III or IV.

[c] Treatment intensity: 1=surgery only; 2=surgery plus radiation or chemotherapy; 3=surgery plus radiation plus chemotherapy.

[†] p<.05; [††] p<.01; 1-tailed

Table 18

Correlation Matrix for Spouse Predictor Variables (n=40).

	1	2	3	4	5	6	7	8	9	10
1. Age (Yrs)		.-13	-.31*	.00	-.10	-.13	.11	.40*	.15	.27
2. Gender (F=1; M=0)			.27	.05	-.29	.00	.21	.00	.03	.05
3. Stage[a,b]				-.21	.38*	-.05	.28	-.06	-.05	-.01
4. Time Since Surgery (Yrs)[a]					-.25	.25	.07	-.26	-.12	-.33*
5. Treatment Intensity[a,c]						-.04	.27	-.03	-.05	.11
6. CES-D							.29	.69**	-.31	-.39*
7. Stigma								-.32*	-.02	.04
8. SOC									.28	.36*
9. Mutuality										.79**
10. Dyadic Adjustment										

[a] These data describe the type of patient treatment for the 40 spouses who completed questionnaires. For 7 of the spouses, the patient did not return a questionnaire but had tumor registry data available.

[b] Stage: II, III or IV.

[c] Treatment intensity: 1=surgery only; 2=surgery plus radiation or chemotherapy; 3=surgery plus radiation plus chemotherapy.

*p<.05; **p<.01; 2-tailed.

Spouse Demographic Variables

The two demographic predictor variables for spouses included age and gender. There was no association between spouse age (r=.07) and global QOL or spouse gender (r=-.11) and global QOL.

Spouse Illness-Related Variables

Illness-related variables for spouses included the patient's disease severity at diagnosis, time since initial surgery, and treatment intensity. None of the associations between illness-related variables–disease severity at diagnosis, time since initial surgery, or treatment intensity and spouses' global QOL was significant.

Spouse Characteristics

Spouse characteristics include depression, stigma, and sense of coherence.

Depression. The association between depression, as measured by the CES-D, and global QOL for spouses was negative (r=-.53; p=.000). Spouses with higher depression scores reported lower levels of QOL. Thirty-five per cent scored 16 or greater. On the CES-D.

Stigma. There was no significant association between spouses' perceived stigma and global QOL (r=-.26).

Sense of coherence. There was a positive correlation between SOC and QOL with the spouses (r=.57; p=.000). Spouses with a greater SOC reported higher QOL.

Spouse Dyadic Variables

Mutuality and dyadic adjustment are the two dyadic variables for spouses.

Mutuality. Pearson correlation analysis revealed a positive correlation with global

QOL for spouses (r=.46; p=.003). Spouses' relationship with the care receiver is associated with higher levels of QOL.

Dyadic adjustment. A positive correlation was observed between dyadic adjustment and global QOL for spouses (r=.53; p=.001). Spouses who report better marital relationships also report higher QOL.

Major Findings for Aim 3

The main findings related to Aim 3 were that no significant correlations were observed between spouses' global QOL and demographic variables or illness-related variables. Depression was negatively correlated with spouses' global QOL(r=-.53). Spouses' perceived stigma was not correlated with QOL. A positive correlation was found between SOC and QOL (r=.57; p=.000). Both mutuality (r=.46; p=.003) and dyadic adjustment (r=.53; p=.001) were correlated with global QOL in spouses.

Table 19 shows spouse QOL regression with the global QOL Scale as the dependent variable. The order of entry was the same for this regression as that for the patients, except that the UW-QOL Scale was not used as one of the spouse predictors. All other predictors were entered in the same order. At entry, the standardized betas (β) revealed that depression carried the heaviest amount of weight (β=-.52), which implies that, for every 1 standard deviation rise in depression, spouse global QOL declines by .52 SD units of measurement. SOC carried the next highest weight (β=.52), followed by dyadic adjustment (β=.41).

An examination of the R^2 change values revealed that depression added the greatest amount, 21.9%, to the explained variance in global QOL after controlling for the previously entered predictors (p<.05). Sense of coherence accounted for an increment of 10% of the variance in spouse global QOL, followed by mutuality (9.1%).

Table 19

Predictors of Spouse Global Quality of Life: Multiple Regression Summary (N=39).

Step	Variable	β weight at entry	R^2 Change	R^2	Adj R^2
1.	Stage[ab]	-.171	.029	.029	.003
2.	Years Since Surgery[a]	-.240	.055	.084	.033
3.	Treatment Intensity[ac]	-.208	.035	.119	.044
4.	Age	-.009	.000	.119	.016
5.	Gender[d]	-.003	.000	.119	-.014
6.	Stigma	-.181	.026	.146	-.014
7.	Depression	-.523	.219*	.365*	.221
8.	Sense of Coherence	.518*	.100*	.464*	.321
9.	Mutuality	.329*	.091*	.555*	.417
10.	Dyadic Adjustment	.406	.047	.602*	.460

Note. Adj = Adjusted.

[a] These data describe the type of patient treatment for the 40 spouses who completed questionnaires. For 7 of the spouses, the patient did not return a questionnaire but had tumor registry data available.

[b] Stage: II, III or IV.

[c] Treatment intensity: 1=surgery only; 2=surgery plus radiation or chemotherapy; 3=surgery plus radiation plus chemotherapy.

[d] Gender: 0 = Male, 1 = Female.

*$p<.05$

Table 20 displays a more parsimonious model for predictors of spouse global QOL. At entry, the standardized betas (β) revealed that depression carried the heaviest amount of weight (β=-.53), which implies that, for every 1 standard deviation rise in depression, spouse global QOL decreases by .53 SD units of measurement. Sense of coherence carried the next highest weight (β=.40), followed by mutuality (β=.32), and finally dyadic adjustment (β=.23). In examining the R^2 change values, it was determined that depression added the greatest amount (27.7%) to the explained variance in global QOL. Sense of coherence accounted for 9.2% of the explained variance. Mutuality accounted for an increment of 9.2% of the explained variance in spouse global QOL after controlling for depression and SOC.

Table 20

Predictors of Spouse Global Quality of Life: Multiple Regression Summary--

A More Parsimonious Model (N=39).

Step	**Variable**	**β weight at entry**	**R^2 Change**	**R^2**	**Adj R^2**
1.	Depression	-.526*	.277††	.277*	.258
2.	Sense of Coherence	.398*	.082†	.359*	.324
3.	Mutuality	.322*	.092†	.451*	.404
4.	Dyadic Adjustment	.230	.019	.469*	.407

Note. Adj = Adjusted.

*p<.05

††p<.05, ††p<.01; 1-tailed

Qualitative, Open-Ended Questions

Respondents were asked a series of open-ended questions at the end of the questionnaire. These were included to determine if anything was missed in the participants' experience that was not reflected in the quantitative items. These questions asked for the respondents to indicate what had been the most difficult for them, what had been the most helpful, and what advice they would give to others who are about to go through an experience such as theirs. The final question asked them to offer any other information that they wanted to reveal about the quality of their lives since the surgery.

Responses to these questions were subjected to content analysis, using the guidelines supplied by Krippendorf (1980). The unit of analysis was a phrase containing a specific response to the question. Categories for classification were identified after carefully reading the responses. Responses frequently contained more than one phrase and were coded into more than one category. The data and categories are summarized in Table 21. The actual responses from patients and from spouses are included in Appendix H.

The most frequent category of difficulty reported by patients was functional problems including eating, speech and hearing. They listed support from others (spouses, family, friends, support groups and health care professionals) as the most helpful for them. When asked what advice they would give others in this situation, patients most frequently replied that one should prepare. For example, one patient wrote: "Get the best doctors available and trust them to make the right decisions." Another patient commented: "Avoid surgery and radiation–use only as a last choice."

In the space provided at the end of the questionnaire, the fourth question, participants were asked to expand upon the quality of their lives since surgery, patients reported functional difficulties most frequently, followed by the impact of cancer on their lives. Following are two examples of patients' responses. "Head and neck cancer is devastating. It affects not only your health and body but overlaps into self-image, appearance, ability to speak and to eat–two very basic and important functions. It is so "out there" you can't hide it under clothes. Head and neck cancer affects a patient's whole life and self-perception."

Another patient wrote: "It has been almost a year since my surgery and I am concerned and disappointed that I can't eat (swallow) most solid foods. My wife and I can't go to most of our favorite restaurants or accept invitations for dinner with friends or relatives. We used to go out to dinner once a week–now we can't and I'm sure my wife is unhappy about it. We miss our weekly "date" for dinner out. The radiation treatments (35) have destroyed my mouth. I have very little taste for most foods and consequently don't want to eat. But probably the most annoying thing is the dry mouth. I have to have a bottle of water with me at all times which means I have to urinate quite frequently. At any rate, in spite of these annoying side effects, I am very happy to be alive and Praise God Daily!"

The most frequent category of difficulty for spouses was watching the patient suffer. The spouses listed support from others (friends, family and spouse) as being the most helpful for them. They also most frequently advised someone who was about to go through an experience similar to theirs to prepare. Here are three examples that spouses wrote in response to this question: “Be prepared for physical changes,” “Be prepared to make adjustments,”and “Find out all you can about what to expect. Ask lots of questions to understand what is happening. The more you understand the better.”

In the space at the end of the questionnaire, the spouses listed their concern about the patients’ health most frequently, wrote about the positive and negative aspects of their marital relationships, and lamented the unexpected outcomes and loss of a normal life. Here are a few examples from the spouses: “It might be apparent from my answers that there has not been a lot of emotional closeness in our 31 years of marriage. This illness, as well as her serious illness in 1989, have further eroded that situation and her health has become the major priority in our lives.” Another spouse wrote: “When something like my wife’s cancer of the jaw bone happens, it changes the whole eating and cooking habits of the house. Because sometimes you are unable to have false teeth in either the upper or lower and combined with radiation, the burning of the mouth makes it impossible to eat right.”

Table 21

Summary of Content Analysis: Open-ended questions and number of participants mentioning each category (n=40 patients and 40 spouses).

Question	Patient	Spouse
1. Thinking of your experience, what has been the most difficult part for you?	Functional difficulty (24) Eating (14) Speech (9) Hearing (1) Effects of treatment (5) Fear (3) Recurrence (2) Surgery (1) Loss of normal life (3) Acute period (3) Dealing with cancer (2) Getting back to normal (2) Keeping a positive attitude (1) Decreased socialization (1) Lack of information (1) Depression (1) Pain (1) Uncertainty (1) No ambition (1)	Watching the patient suffer (10) Caregiving (8) Physical care (4) Managing / organizing care (2) Taking on responsibility / encouraging (2) Uncertainty (3) All of it (3) Marital relationship (3) Communication (2) Dealing with cancer (1) Acute period (2) Lack of information (2) Financial (1) Anticipatory loss (1) Recurrence (1)

Question	Patient	Spouse
2. What has been the most helpful for you during this experience?	Support from others (43)	Support from others (23)
	Spouse (12)	Family (10)
	Family (10)	Friends (9)
	Health care professionals (10)	Spouse (4)
	Friends (7)	Health care professionals (13)
	Support group (2)	Spirituality (6)
	Success of treatment (3)	Marital relationship (1)
	Keeping a positive attitude (2)	Keeping a positive attitude (1)
	Keeping busy (2)	Gathering information (1)
	Spirituality (2)	
	Adjusting to disfigurement (1)	
	Determination (1)	
	Time (10)	
3. What advice would you give others who are about to go through an experience similar to yours?	Prepare (24)	Prepare (12)
	Medical advice (12)	Medical care advice (7)
	What to expect (9)	Gather information (5)
	Gather information (3)	Positive attitude (8)
	Keep going (9)	Keep going (7)
	Keep a positive attitude (7)	Be supportive (6)
	Spirituality (5)	Spirituality (5)
	Rally support from others (3)	Reach out to others (5)
	Talk with a "veteran" (1)	Keep busy (1)
		Care for yourself (1)

Question	Patient	Spouse
4. Please use the space below if there is any other information that you would like to tell me or you think I should know about the quality of your life since the surgery.	Functional difficulties (15) Eating (8) Speech (4) Dry mouth (3) Impact of cancer (9) Quality of life unchanged (3) Pain (1) Time (5) Decreased socialization (4) Spirituality (2) Unhappy with results of surgery (1) No support group (1) More treatment to go (1)	Concern about patient's health and physical sequelae (4) Marital relationship (3) Loss of normal life and employment (2) Unexpected outcomes (2) Caregiving (1) Questionnaire comprehensive (1) Appreciation of health (1) Caregiver also ill (1) Recurrence of cancer (1) Regrets about medical care (1) Encouraged about patient quitting smoking (1) Dealing with care receiver's other illnesses (1) Spirituality (1) Coping (1) Annoying treatment by others (1)

Summary

This study used a descriptive correlational design to describe the level and pattern of QOL and stigma reported by head and neck cancer patients and their spouses, and to examine the relative importance of illness-related, patient, spouse, and dyadic variables in explaining quality of life as an outcome for head and neck cancer patients and their spouses. Measures were obtained at one point in time during the first 6 years after initial surgery for head and neck cancer. The sample consisted of 33 patients and their 33 spouses, 7 patients with no linked spouse, and 7 spouses with no linked patient. Descriptive statistics were used to analyze study data. Major findings include the following.

Patients reported the highest satisfaction with life on UW-QOL Scale items relating to pain, swallowing, and shoulder disability. Chewing was ranked as the most difficult issue for them. Patients reported being most satisfied with life on the global QOL Scale in the area relating to relationships with close family members and friends. Responses on the Stigma Inventory indicated that more patients agreed in areas relating to their appearance, having to "break the ice" on social occasions, and sensing others' perceptions of the illness.

Spouses also rated relationships with close family members and friends highly, but indicated that having and rearing children was the most satisfying. More spouses agreed in areas relating to others being embarrassed to ask about the patient's illness, and sensing that others did not know how to react to the patient's illness. Items ranked the highest by both patients and spouses related to others judging them, or others' reactions to the illness.

In summarizing the correlations, the following was observed: (a) the only demographic variable (of age and gender) that was significantly correlated with QOL was that of female patient gender; (b) illness-related variables (disease severity, time since surgery, and treatment intensity) were not significantly correlated with QOL in patients or in spouses; (c) depression was inversely correlated with global QOL for both patients and spouses, and with patients' disease-specific QOL; (d) an inverse relationship was found between patients' perceived stigma and global QOL, but not for the spouses; (e) the highest correlations were observed between SOC and global QOL for both the patients and the spouses; and (f) no relationship was found between the dyadic variables for the patients (mutuality and dyadic adjustment) and QOL (global or disease-specific). However, both mutuality and dyadic adjustment were positively correlated with spouse global QOL in this sample.

In the more parsimonious regression model for the patients using the UW-QOL Scale as the dependent variable, depression carried the highest beta weight at entry (β=-.43). Depression accounted for the greatest increment in the explained variance (12.5%) in disease-specific QOL, after controlling for 3 other predictors.

In the more parsimonious regression model for the patients using global QOL as the dependent variable, the highest beta weights at entry were observed on variables including UW-QOL (β=.49) and gender (β=.38). The UW-QOL Scale accounted for the greatest increment in the explained variance in global QOL (22.1%), followed by female gender (13.8%).

The regression analysis for the spouses, using global QOL as the dependent variable, revealed that the highest beta weights were observed on variables including depression (β=-.53) and SOC (β=.40). Depression (27.7%), mutuality (9.2%) and SOC (8.2%) accounted for a significant increase in the amount of explained variance in global QOL for the spouses in this sample.

Chapter 5

Discussion

In this chapter the findings are interpreted. The limitations of the study are discussed, along with the implications for nursing theory, practice and research.

Aim 1

The purpose of Aim 1 was to describe the level and pattern of QOL and stigma reported by head and neck cancer patients and their spouses.

Patient disease-specific QOL. Pain, swallowing and shoulder disability represented the highest means for QOL (higher indicating better QOL) in this sample. Although 47.5% of the patients in this sample reported the best achievable score in the area of chewing, the mean for that item was among the lowest. A possible explanation for a low mean on this item may be that approximately half of the patients in this sample were diagnosed with oral cancer, and 68% presented with stage III or IV at diagnosis. Patients in this sample contained a disproportionately greater number of oral cancer sites compared to the percentage eligible from the two Tumor Registries. A more advanced stage would indicate that more extensive surgery involving the mandible would be the likely course of treatment. Reconstructive surgery of the mandible changes the configuration of the jaw. False teeth must be worn and they may not fit well, or may irritate the mouth and interfere with chewing. Considering the cancer site being in the mouth, along with the severity of disease, it is understandable that patients would report more difficulty with chewing. Patients reported disfigurement as being the area that represented the lowest QOL. One possible explanation for this may be that almost half of the patients reported being employed. If they are dealing with the public, they may consider their disfigurement to be important when determining the quality of their lives. Disfigurement is a subjective perception (Dropkin, 1999), and may be very important, regardless of employment status. If one perceives that his or her disfigurement is great, it may affect self esteem or social interactions. In a study of 48 head and neck cancer patients at 3 different points in time, Rogers, Lowe, Brown and Vaughan (1999) found that, at 12 months, shoulder dysfunction represented the highest mean, followed by speech, and then swallowing difficulty. Patients in their study had the most difficulty with employment, followed by activity and then recreation. Chewing and swallowing were among the highest scored items for them. Also in that study, the items that had the greatest percentage of best achievable results were items relating to shoulder dysfunction, speech and disfigurement.

The qualitative responses of the present study confirm these results. Patients indicated that functional problems (eating, speech, and hearing) were the most difficult for them. Again in the final open-ended question, when asked to comment on the quality of their lives since surgery, patients responded most frequently that functional difficulties were paramount with them.

Patient global QOL. The original Flanagan (1983) version of the QOL Scale had 15 items. Most of the Burckhardt QOL references published so far have used the 15-item scale. This study used the 16-item scale which also includes Independence, being able to do things for yourself, which is appropriate for individuals with chronic illness. The scale has not previously been used with persons with cancer. In addition, the levels and patterns of responses on the QOL Scale have not been reported for this population. In this sample, head and neck cancer patients reported being generally satisfied with the quality of their lives. These findings are consistent with other studies of this population. Kreitler, Chaitchik and Rapoport (1993) found no difference in life satisfaction between head and neck cancer patients, orthopedic patients, and healthy patients. In another study of 50 head and neck cancer patients using 3 disease-specific instruments, Long and his colleagues (1996) reported similar findings of fairly high QOL scores with head and neck cancer patients.

Global QOL scores for this sample may be compared with those reported in the literature. Burckhardt, Archenholtz and Bjelle (1993) assessed QOL (using the global QOL Scale) of 50 women with systemic lupus erythematosus (SLE) and 50 women with rheumatoid arthritis (RA). The mean QOL score for the group of women with SLE was 86.1 (SD=13.6), and the mean score for the RA group was 83.3 (SD=9.6). In another study of 149 individuals with heart disease surviving cardiac arrest, Underhill (1992) found the mean score on the global QOL Scale to be 84.8 (SD=14.4). The scores for this sample were similar, with patients' mean score being 85.6 (SD=9.6).

Spouse global QOL. In 10 of the 16 areas of QOL, 82% or more of the spouses reported being satisfied. Spouses ranked having and rearing children as the most satisfying, followed by relationships with family and close friends, and then activities that keep them close to home. In 6 areas, only 47% to 72% of spouses were satisfied. These items included getting out and associating with individuals other than those close to them. Although the literature suggests that spouses may be adversely affected by the illness experience (Krisjanson & Ashcroft, 1994), findings from this sample reveal that, in general, spouses report being fairly satisfied with the quality of their lives, particularly in areas relating to having and rearing children, close relations with their spouse or significant other, reading, music and watching entertainment, and being independent. Spouses reported the areas least satisfying included being out and about–participating in public affairs and active recreation. Interestingly, health was listed among the least satisfying areas for them. In the qualitative responses, two spouses remarked about their own health–one spouse confided that she was not well; another commented on an appreciation for health.

On the global QOL Scale, spouses' mean score was 86.1 (SD=9.9) for this sample. No data are reported in the literature on family members using the QOL Scale for comparison. A possible explanation for spouses reporting such high QOL scores may be that they have found meaning in their lives in spite of their circumstances. They may have found support resources which may have contributed to the quality of their lives.

Patient stigma. On the item pertaining to being afraid that their illness may affect the way people judge their performance at work, working patients reported higher stigma and than non-working patients, and 54% of working patients endorsed the item at the level of mild to strong agreement. Only 14% of non-working patients reported agreement on this item. Sixty-five per cent of the patients in this sample reported that they were retired . For use of this scale with older populations, it is suggested that this item be deleted. Patients ranked items the highest (more stigma) that related to others judging them or others being embarrassed to ask about their illness. Although the qualitative responses do not appear to support this finding, a larger sample may have confirmed this.

Spouse stigma. Spouses in this sample, in general, do not report perceiving that the patients are highly stigmatized. The qualitative responses lend support to these findings. Whereas patients reported decreased socialization among the most frequent issues affecting the quality of their lives, spouses did not report issues that relate to the concept of stigma, as defined by Goffman (1963). Instead, they were more concerned with issues relating to the patients' suffering and aspects of caregiving.

On the item pertaining to being afraid that the illness may affect the way people judge the patient's performance at work, spouses of working patients reported higher stigma and than spouses of non-working patients, and 33% of spouses of working patients reported agreement (mildly agree to strongly agree). Only 8% of the spouses of non-working patients reported agreement on this item. This may be because the spouses are concerned that the patient is viewed by co-workers as no longer able to perform his or her work requirements. The spouses may believe that the patient is judged poorly because of the illness and that others may stigmatize the patient. Spouses may be concerned that the patient's job may be in jeopardy because of others' judgements. On three of the ten items on Subscale 1 (Social Presentation and Social Interaction), only 25% to 32% of the spouses reported agreement in the areas relating to sensing that others are embarrassed to ask about the patient's illness, that others don't know how to react, and that they (spouses) needed to "break the ice" on social occasions.

Aim 2

The purpose of Aim 2 was to examine the relative importance of three sets of variables in explaining QOL as an outcome for head and neck cancer patients.

The UW-QOL Scale added the greatest amount (22.1%) to the explained variance in global QOL after controlling for treatment intensity and gender. Scores on the UW-QOL Scale for patients in this sample should be considered with caution when comparing them with other studies because the item of employment was removed. With the removal of this item, the total scale score is reduced by 100 points. Instead of the range of scores being 0 to 900, the range for the scale is 0 to 800. Within the subscale of employment, one of the items asks if the respondent is retired due to cancer treatment. These may be very important issues to consider when evaluating the scores. Having to retire due to cancer treatment may have a great impact on an individual's perception of the quality of their life. The average UW-QOL score for this patient sample was 585; patients reported better QOL scores than those found in the literature. The average UW-QOL score reported in a study of 50 head and neck cancer patients was 556 (Long et al., 1996). In another study of 48 head and neck cancer patients, the average score was 671, as reported by Rogers, Lowe, Brown, and Vaughan (1999). The high patient scores on the UW-QOL Scale for this sample do not appear to be supported by the qualitative responses. Because functional difficulties such as eating, speech and hearing were reported as the most frequent difficulty, we would expect the scores on the UW-QOL Scale to have been lower in those areas.

Depression (r=-.42) and stigma (r=-.31) were correlated with UW-QOL. Depression has also shown a significant negative correlation to the UW-QOL Scale in a study of 50 head and neck cancer patients 6 months to 6 years after surgery by D'Antonio and her colleagues (1998), who found a negative correlation (r=-.44; p=.033) between depression and UW-QOL. Of the predictor variables in the present study, depression was the most helpful in explaining patients' disease-specific QOL ($R^2\Delta$=.125).

Depression scores from this sample may be compared with those reported in the literature. In this sample, the total depression score for patients, using the CES-D, was 11.26 (SD=7.5). Hann, Winter and Jacobsen (1999) compared depression scores of cancer patients–117 women with breast cancer and 62 women with no history of cancer prior to treatment and during treatment. During treatment (radiation, chemotherapy or bone marrow transplantation), CES-D mean score for patients was 12.8 (SD=10.2). The mean score for women with no breast cancer was 7.8 (SD=7.5). The cut-off point for triggering a full assessment of clinical depression is a score of 16 or higher (Radloff, 1977). In a descriptive survey of 60 men with life-threatening illnesses (30 had cancer and 30 had AIDS), ages 18-55, the mean depression score was 17.4 (SD=7.4) (Servellen, Sarna, Padilla & Brecht, 1996). In a sample of older adults, Murrell, Himmelfarb and Wright (1983) reported data for 2,517 community dwelling individuals over 55 years of age. Mean CES-D scores for males was 9 and for females the mean score was 11. Mean scores for both genders increased at age 75. In an integration of studies using the CES-D, Radloff and Teri (1986) concluded that more females than males report higher CES-D scores, regardless of age.

Stigma was correlated with both disease-specific (r=-.31) and global QOL (r=-.31) for the patients. Strauss (1989) reported that in intensive interviews with head and neck cancer patients, 57% reported feeling stigmatized or discounted because of their appearance but, with the passage of time, came to accept it. None reported taking steps to hide their appearance. It may be because they had incorporated into their lives the steps to hiding their appearance such that they did not realize the extent to which they had concealed the scars or changes in the shape or symmetry of their face as a result of surgery (personal communication, L. Nail, December, 2000).

It was hypothesized that female patients would report a lower QOL, but female patients in this sample reported a significantly higher QOL (r=.40), with gender accounting for 13.8% of the explained variance in global QOL after controlling for treatment intensity. Some studies have shown that males report a higher QOL (Koller, Heitmann, Kussman, & Lorenz, 1999). No significant differences were found between gender and QOL in a study of 50 head and neck cancer patients (Long et al., 1996). When considering demographic variables in the regression analysis, we need to think complexly about what the variables mean. For example, age and gender are more than just what the numbers seem. We must consider the cohorts that people are a part of (e. g., people that went through the depression), and consider if there is anything about the way men and women are socialized that may account for the differences in gender. Because of the limited sample size, we should have strong reservations about interpreting demographic variables unless we are confident that the sample is representative and large enough (personal communication, B. Stewart, November, 2000). In comparing these results with the qualitative responses, it is noted that patients reported support from others as being the most helpful for them during this experience. One possible explanation for the finding that females report better QOL may be that they believe that they are receiving adequate support from others, and value that support.

Although SOC did not explain a significant increment in the explained variance of QOL in patients, it was moderately correlated with patient global QOL (r=.50). One possible explanation may be that the patients are focused on the functional difficulties resulting from treatment, and allow their spouses to be concerned with the aspects of SOC, such as managing, comprehending, and understanding, which are the 3 dimensions of SOC. Sense of coherence, however, was found to be a strong independent predictor of global QOL in a study of 149 persons surviving cardiac arrest, explaining a 15%

increment after controlling for 5 other predictors (Motzer & Stewart, 1996).

No relationship was found between patient dyadic variables (mutuality and dyadic adjustment) and QOL. One possible explanation may be that the patients in this sample are so focused on the functional difficulties (e.g., chewing) and disfigurement, that the marital relationship may not be uppermost in their minds. However, Long and his colleagues (1996) reported that being married was correlated with general QOL in their study of head and neck cancer patients. They concluded that marital status is an important factor to consider in discharge planning.

In evaluating the qualitative responses, the most frequent category of difficulty reported by patients was functional problems including eating, speech and hearing. They listed support from others (spouses, family, friends, support groups and health care professionals) as the most helpful for them. When asked what advice they would give others in this situation, patients most frequently replied that one should prepare. Some examples relation to this item include offering advice about medical care, what to expect, and gathering information.

Aim 3

The purpose of Aim 3 was to examine the relative importance of three sets of variables in explaining QOL as an outcome for the head and neck cancer spouse.

The main findings related to Aim 3 were that no significant correlations were observed between spouses' global QOL and demographic variables or illness-related variables. Depression was negatively correlated with spouses' global QOL ($r=-.53$). Spouses' perceived stigma was not correlated with QOL. A positive correlation was found between SOC and QOL ($r=.57$; $p=.000$). Both mutuality ($r=.46$; $p=.003$) and dyadic adjustment (r=.53; p=.001) were correlated with global QOL in spouses. In examining the R^2 change values, it was determined that depression added the greatest amount (27.7%) to the explained variance in global QOL.

Sense of coherence accounted for an increment of 8.2% in the explained variance of spouse global QOL. These findings are consistent with those in a study of 42 newly diagnosed cancer patients and 32 spouses. Mullen, Smith and Hill (1993) found that SOC was a predictor of psychological stress in patients and in spouses. In this sample, mutuality accounted for an increment of 9.2% of the explained variance in spouse global QOL after controlling for depression and SOC. The qualitative responses confirm these findings. When asked what advice they would give others, spouses reported that one should keep a positive attitude, keep going, be supportive, trust God, and reach out to others.

Comparison of patients' and spouses' responses. Of the patient predictor variables, depression was the most helpful in explaining patients' UW-QOL. For the parsimonious global QOL model, of the patient predictor variables, female gender and the UW-QOL Scale were the most helpful in explaining patients' QOL. Of the spouse predictor variables, depression was the most helpful in explaining spouses' global QOL, followed by SOC and mutuality.

Depression is an important issue for the patients as well as the spouses in this sample in relation to the quality of their lives. Significant correlations were found between patient depression and QOL (both disease-specific and global), and between spouse depression and global QOL. In addition, for patients, depression accounted for a 12.5% increment in the explained variance in disease-specific QOL. In a study of the relationship between depression and QOL in head and neck cancer patients, depression was shown to have a significant negative correlation to UW-QOL (r=-.44, p=.003) (D'Antonio et al., 1998). However, in a review of the literature of physical and psychosocial correlates of head and neck cancer, deBoer and his colleagues (1999) conclude that reports about prevalence of depression in this population are inconsistent.

There may be many possible explanations as to why depression was such a powerful predictor of QOL in this sample. Other illnesses or conditions, in patients or spouses, may contribute to feelings of depression. Relationships with others, within the family or outside, may influence perceptions. Stressors such as role changes or financial worries may also account for the high depression scores in this sample. In a discussion of using depression scales with the elderly, Kane and Kane (1981) explain that the construct of depression may be viewed differently by older individuals than by younger ones. Factors such as poor health may be more predominant with older people. Symptoms associated with poor health may lead to depression. Spouses' depression scores were higher than those of the patients in this sample. The mean depression score, using the CES-D, for spouses in this sample was 13.49 (SD=8.96). This is consistent with findings from a longitudinal study of couples' adjustment to colon cancer (Northouse, Mood, Templin, Mellon & George, 1999). Spouses reported significantly more emotional distress and less social support than patients at one week post-diagnosis, at 60 days and one year post surgery.

A positive correlation was found between spouse mutuality and QOL and spouse dyadic adjustment and QOL. However, the correlations between mutuality and QOL and dyadic adjustment and QOL were not significant for the patients in this sample. The low inter-item correlations between item # 5 on the patient QOL Scale (close relations with spouse) and other QOL items (helping others, participating in organizations, learning, job: work or home, expressing yourself creatively, and health) confirm the low correlations between mutuality and QOL and dyadic adjustment and QOL. It appears that spouses consider the quality of the marital relationship to be more satisfying than the patients do in this sample.

The qualitative responses also support these findings. Spouses reported that the most difficult part of their experience had to do with the patient–watching the patient suffer, and caregiving. The marital relationship was also listed among the most frequently reported difficulties by spouses. These responses, along with the quantitative data suggest that spouses in this sample consider the patient and the marital relationship to be important factors in the quality of their lives.

In comparing the patients' responses with those of the spouses in this sample, it appears that the patients do not consider the quality of the marital relationship to be as important for the quality of their lives as do the spouses, and that spouses in this sample do not sense the extent of stigma that is perceived by the patients. Goffman (1963) suggests that persons close to the stigmatized one may develop a "courtesy stigma" and may also develop strategies to handle it. The "courtesy stigma" was not apparent with the spouses in this sample. The concept of stigma does seem to be a salient one in head and neck cancer patients and, with a larger sample, it may be further explored.

Limitations

The limitations to this study include threats to internal and external validity. Internal validity refers to the extent to which the independent variable is truly influencing the dependent variable (Burns & Grove, 1997). In this study, sample selection bias posed a threat to internal / external validity. Couples self selected themselves by the willingness of both patients and spouses to participate. Couples were asked to complete the questionnaires individually and not to share their answers with each other. Each person had a separate return envelope. However, there was no way to know that couples followed this request. Another issue related to sample selection was that, in the cover letter, both the patient and the spouse were asked to participate. Some individuals who may have been willing to respond may have chosen not to simply because their spouse did not. The greatest limitation to sample selection was the exclusion of those who were either unable or unwilling to participate. This created a sample bias of respondents who were healthy enough and / or willing to participate. The responses of those who are too ill, too stressed, too unhappy, or unwilling are not represented.

The sampling inclusion criteria posed another threat to internal validity for this study. The argument was made that range of time would be 0 to 6 years since the date of the patient's surgery. A cross-sectional was intended to compare patients' and spouses' responses across different variables, such as age, stage, time since surgery, etc. However, using a cross-sectional approach for such a long time span does not allow a clear picture of the relationship of the predictors to the outcome (QOL) to become apparent–intervening variables and adaptive processes may "disturb" the relationship. A longitudinal study would follow the same head and neck cancer patients and their spouses at different points in time, allowing for changes to be examined. A clearer relationship between QOL and factors that influence it may be ascertained.

Another threat to internal validity is the measures. A new scale–The Stigma

Inventory–was used. Reliability and validity of this measure have not been established, and it has not been used with individuals with cancer. With this sample, many of the inter-item correlations for the Stigma Inventory were either close to zero or were negative, indicating that the items do not "fit" together in the scale under the construct of stigma. Research has not yet developed the concept of stigma to determine the strength of validity for this instrument. Another controversial measure that was used was the DAS. Although it has been used in other chronic illness groups, its use in this sample may be questionable. Two respondents indicated that the questions were "too personal." It may be because other items in the survey, such as those on the Stigma Inventory may have touched on personal issues, and the combination of those with marital difficulties may have deterred responses. Kane and Kane (1981) suggest that older individuals "have narrowed opportunity for sexual expression" (p. 109). It may be because of cohort views–older persons may not feel comfortable discussing their personal marital issues with strangers.

External validity refers to the ability to generalize the findings. This sample may not be representative of head and neck cancer patients and their spouses for several reasons. First, the study proposed a representative percentage of each of the cancer tumor sites (oral, pharynx and larynx). However, this sample differed in comparison with the per cent eligible from the Tumor Registries. In this sample, 51% of the patients had oral cancers, compared with 45% in the combined patient data set from the two Tumor Registries. Approximately 20% of the patients in this sample had cancer of the larynx compared with 21% in the combined data set). In describing patient characteristics for a study on head and neck cancer outcomes, Karnell, Funk and Hoffman (2000) reported that their sample was comparable to a national data set of 102,396 patients. Of their sample (n=68), 36% of the patients had oral cancer and 40% had cancer of the larynx. Because it has been reported in the literature that the site of the tumor affects QOL scores (Weymuller et al., 2000), the results of this sample should be interpreted in view of the disproportionately greater percentage of oral cancers and fewer laryngeal cancers. Weymuller and his colleagues found that, at 3 months, patients with oral cancers fared worse (lower QOL scores) than those with laryngeal cancers. In a review of the evolution of QOL assessment in head and neck cancers, Morton (1995) maintains that "Given the diverse nature of head and neck cancer, and the heterogeneous nature of the disease- and treatment-specific symptoms it may ultimately be appropriate to stratify for subsites of head and neck cancer when analyzing results" (p. 1033).

Another threat to external validity is the underrepresentation of the most vulnerable patients and spouses from potential sources. First, of the entire population of head and neck cancer patients, we eliminated all who were not married. This excluded from the data set all who do not have a spouse for social support. Second, of the eligible patients and spouses, many did not respond to the survey. It is possible that families who chose not to participate are more vulnerable than those who did participate because they may have been too ill, too fatigued, or emotionally stressed. Their responses are also not represented in this sample.

The sample consisted of individuals who were almost all Caucasian (one spouse was Native American), lived in the Pacific Northwest and had access to health care and were influenced by medical regimens in the Northwest. The findings for patients and spouses living in other geographic regions may not be the same. In addition, support groups are more accessible in metropolitan areas, which may influence the quality of their lives.

The low response rate is another limitation to this study. Although this particular population (head and neck cancer) may be quite ill, and some have died (15 known deaths), there may be other issues affecting them that prevented them from participating. For example, alcohol use may have affected some decisions about participation. In addition, other illnesses may have compounded their stress level. Caregivers may have been too ill or too stressed to complete the forms. Other studies have reported a low response rate. For example, in a descriptive mail survey of 298 breast cancer survivors, a 40% response rate was reported (Ferrell, Grant, Funk, Otis-Green & Garcia, 1998). Similar strategies were undertaken in that study as were in this one. Names were obtained from a Cancer Tumor Registry, and a cover letter was sent with the questionnaires. In their discussion of the low response rate, the researchers suggested that there may be other QOL concerns, and that the need exists to follow up those concerns. In a study of elderly persons with chronic diseases, Pearlmann and Uhlmann (1988) reported a 48% response rate for mailed questionnaires. Other studies with higher response rates have described strategies used, such as personal contact by a nurse or physician at the clinic or a research assistant, and follow-up phone calls. Using the total design method, Dillman (1978) suggests sending a third letter, but this strategy was not used because it seemed too coercive.

Implications for Nursing Theory, Practice and Research

Implications for nursing theory. As a result of the ambiguity surrounding the concept of QOL, decisions regarding its operationalization have lacked a basis of theory

(Mast, 1995). Padilla and Grant (1985) have suggested the need for a sound theoretical basis for use of QOL as an outcome variable in nursing studies. Mast (1995) encourages nurse researchers to develop and test theoretical frameworks. One such framework has been developed and is being tested by Ferrell (1996) in her program of oncologic nursing research. King and her colleagues (1997) conclude that, although there is some conceptual agreement, much work still remains in studies of QOL and the cancer experience.

In a literature review on QOL following head and neck cancer, Dropkin (1998) concluded that more recent studies are being conducted with multidisciplinary teams, which is appropriate given the complexities of problems that the patients face. More research is also being done to determine the manner in which head and neck cancer health status domains overlap or differ from each other and from general measures of QOL. This is a promising area of future research, because it may lead to more unity in clarifying definitions and the concept of QOL.

Morton (1995) emphasizes that what is needed in H&N cancer research is "to expand research on the clinical and social usefulness/validity in our QOL measures" (p. 1033). In addition, he summarizes several researchers' comments stressing the importance of H&N cancer patients achieving a good QOL, of researchers continuing to assess patients' subjective QOL perceptions, and of combining survival outcomes with reliable and valid disease-specific instruments. What is needed, according to deBoer and his colleagues (1999), in addition to refinement of disease-specific measures, is further developing and testing of theoretical models.

The results of this study contribute to the understanding of QOL. Patients in this sample reported that disfigurement was the least satisfying, and chewing was the most troublesome functional difficulty. Patients and spouses in this sample reported being fairly satisfied with the global QOL. Neither patients nor spouses reported that they perceived a high degree of stigma in relation to head and neck cancer. Depression is an important issue for both patients and spouses, and spouses report that the marital relationship is very important for them in relation to the quality of their lives.

Implications for nursing practice. The findings of this study have implications for clinical practice. Clinicians should be reminded of the importance of assessing for functional difficulties of head and neck cancer patients after surgery. People in this study are generally happy with their spouse, so marital discord does not appear to be a difficult issue with them. However, findings of this study may serve to sensitize clinicians as to what the issues are. Long-term effects of head and neck cancer treatments should be considered when implementing plans of care, both for patients and for spouses. Functional difficulties for patients, such as problems with chewing, must be assessed because nutritional problems may occur. Social relationships may also be altered as a result of the problems in eating. In view of the high depression reported by both the patients and the spouses, it is important for clinicians to be screening for depression, and to consider spouses also when evaluating head and neck cancer patients.

Implications for nursing research. In her discussion of future directions for cancer studies, Ferrell (1999) maintains that there has been a serious lack of attention to geriatric oncology, and there has been a recognizable bias against its development. She challenges researchers to attend to issues relevant to the union of geriatrics and oncology in view of the increasing older population. The results of this study suggest that individuals 50 years and over (and their spouses) must be represented in QOL studies of head and neck cancer.

Among the recommendations for future research is the need for more qualitative studies from the participants' point of view (King et al., 1997). The concept of stigma and cancer may be explored, and an instrument developed, or revised, that undergoes rigorous psychometric testing, and may be used in a variety of cancer studies. Qualitative studies are needed which describe and expand the variables for testing, and possible future intervention within the marital relationship. Although there are challenges to longitudinal designs with individuals that are very ill, prospective studies may be able to detect salient issues that affect the quality of the lives of head and neck cancer patients and their spouses at pivotal points in time. There may be contextual factors that affect scores (e.g., recent surgery, current radiation). Differences in symptoms by location of cancer and their effect on QOL is a potential area for exploration. Specific points of interest may be: when do the shifts in QOL scores occur or, to what extent do they change?

Another gap in the head and neck cancer QOL literature is the need for studies about patient/spouse relationships and how the cancer experience affects spouses as well as the patients. Spouse caregivers are most likely women, since most elderly men are cared for by their wives, and elderly men are more likely to get head and neck cancer (American Cancer Society, 1997; Vaughan, Fitzgerald, Vlock, Vergo, & Costello, 1996). Spouses may be the link between the patient and health care professionals. Therefore, it is important to understand how their unique relationship may be altered by such a traumatic event as head and neck cancer.

This study did not propose a comparison of the differences between patients' and spouses' perceptions of QOL or of any of the independent variables because the purpose was to determine predictors of QOL. Future studies may examine these differences. Future research may also include variables that examine the use of alternative medicine. In a recent review, it was concluded that, on average, 31% of cancer patients reported the use of alternative medicine (Ernst & Cassileth, 1998). It is suggested that longitudinal studies are needed to follow patients along the course of their illness and/or recovery to gain a clearer picture of specific factors that affect QOL (de Boer et al., 1999; Morton, 1995). However, people living with chronic illnesses such as cancer will differ in their ability to expend energy on their illness at varying points in time. For example, persons who have recently undergone surgery or radiation may be unable to complete a questionnaire. Caregivers may experience these variations as well. Likewise, they may be too energy-depleted (either physically or emotionally) to participate in a research study at crucial periods, which prevents them from participating. These critical time points may be under represented and there may inadequate data to conclude that time since initial surgery may significantly correlate with QOL in patients or their spouses.

Quality of life assessment is here to stay, and some maintain that not including it in research, especially clinical trials, poses an ethical problem (Bernhard et al., 1998). More studies are sure to come that will examine the impact of relationships, cultural variables and pre-cancer life experiences on perceptions of QOL. Consensus may be reached as to the parameters to be measured and which methods should be used. In addition, more agreement on QOL terminology and definitions is expected. Future research involving QOL in cancer will also include planning and implementing interventions that are research-based using multidisciplinary teams, and refinement of techniques and instruments used in measuring the complex and multidimensional nature of the concept of QOL. The knowledge base will be expanded and nursing care provided to patients with cancer and their spouses will be improved.

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Appendix A

Cover Letter to Potential Participants

OHSU
SCHOOL OF NURSING

ASHLAND • KLAMATH FALLS • LA GRANDE • PORTLAND

OREGON HEALTH
SCIENCES UNIVERSITY

PORTLAND CAMPUS

3181 S.W. SAM JACKSON PARK RD.
PORTLAND, OR 97201-3098
503-494-7100

[Date]

[Participants' address]

Dear Mr. and Mrs. [Name],

My name is Nadine M. Parker and I am a doctoral student at Oregon Health Sciences University. I am studying quality of life in patients who have had surgery for cancer of the head and neck and for the patient's spouse. If you choose to participate in the study, please complete the enclosed study questionnaires. The enclosed consent forms explain the study's purposes, the importance of your participation, and issues related to confidentiality, risks, and benefits.

You will find two questionnaires in this envelope--one for patient who had surgery for head and neck cancer and one for their spouses. Please complete your booklets on your own because I am interested in your individual opinions. Please do not discuss the questions or the answers with each other until you have mailed the questionnaires back. All information you give will be kept completely confidential.

It usually takes less than one hour to complete the questions. The questionnaires will include items about your experience with the cancer and its treatment, how you personally feel about what your experience means to you and about your relationship with your spouse. On the questionnaire, there are some questions about depression. If your score is very high, I will contact you with that information so that you can decide whether to seek any advice from a professional.

Two self-addressed stamped envelopes are enclosed to return your completed questionnaires to me. **There is one envelope for the patient and one envelope for the spouse. (There is also one consent form for each of you to sign and return with the surveys.)** If you do not wish to participate, simply throw the questionnaires away. However, in the near future, you will be contacted again to give you a chance to reconsider.

Thank you for thinking about completing the survey. The information you provide will assist nurses and doctors to better understand the experiences of patients who have head and neck cancer surgery and their spouses so that care can be improved in the future.

Sincerely,

Nadine Parker

Nadine M. Parker, MS, RN
Doctoral Student, School of Nursing
Oregon Health Sciences University, Portland, OR

Appendix B

Consent Form

OREGON HEALTH SCIENCES UNIVERSITY
LEGACY HEALTH SYSTEMS

CONSENT FORM

TITLE OF STUDY: Quality of Life in Head and Neck Cancer Patients and Their Spouses

PRINCIPAL INVESTIGATOR:
Nadine M. Parker, MS, RN, (503) 494-3840
Doctoral Candidate, Oregon Health Sciences University

CO-INVESTIGATORS:
Patricia G. Archbold, DNSc, RN (503) 494-3840
Barbara J. Stewart, PhD (503) 494-3835
Lisa L. Onega, PhD, RN (503) 494-3885

PURPOSE: You and your spouse have been invited to participate in this nursing research study because nurses and doctors would like to have a clearer understanding of what your life is like on a daily basis. The purpose of this study is to examine how head and neck cancer surgery has affected the quality of your lives. Information from this study may be used by physicians and nurses in the future to prepare patients and their spouses for their experiences after leaving the hospital.

PROCEDURES: You and your spouse are asked to fill out the questionnaires separately. Please do not compare answers while filling them out, but you may discuss the questions and answers together after completing the forms if you wish. Information will be gathered from each of you individually. The questions are similar for each of you and ask about each of your perceptions of your relationship and your experiences since the surgery. The most personal or sensitive questions ask about your relationship and the stigma you may feel. This information will be gathered through written questionnaires. It usually takes less than one hour to complete the questions. The questionnaires may be completed in your home.

You are asked to complete the questionnaire separately and return it in the enclosed, stamped envelope. In one week you will each receive a postcard thanking you or reminding you to return the questionnaire. If you do not return the questionnaire, a second complete packet will be mailed to you seven weeks later. No further contact will be initiated by the investigator after that time.

In addition to your completed questionnaires, the investigator will review your (the patient's) hospital medical records and your (the patient's) clinic records to obtain information related to the surgery and treatment.

RISKS AND DISCOMFORTS: It is possible that some of the questions may upset you or you may become tired. There is some inconvenience associated with the time and effort required to complete the questionnaire.

On the questionnaire, there are some questions about depression. If your score suggests that you are depressed you will be provided information so that you can decide whether to seek any advice from a professional.

BENEFITS: You may or may not personally benefit from participating in this study. However, by serving as a subject, you may contribute new information which may benefit patients in the future.

ALTERNATIVES: You may choose not to participate in this study.

COSTS: There are no financial costs to you associated with this study. You and your insurance company are financially responsible for standard treatment costs incurred while participating in this study.

CONFIDENTIALITY: Your names will not be included on the questionnaire or any of the forms. They will have ID numbers that allow matching your responses with your spouse's responses. Your responses will not be revealed to your spouse by the investigator. Information regarding your participation in this study will be available only to the investigator and her committee members. All precautions to maintain confidentiality of medical records will be taken. Only the investigator and her committee members will have access to identifiable data. You will not be identified by name, picture, or any other identifying information in any publication resulting from this study.

LIABILITY: It is not the policy of the U.S. Department of Health and Human Services, or any federal agency funding the research project in which you are participating to compensate or provide medical treatment for human subjects in the event the research results in physical injury.

The Oregon Health Sciences University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you suffer any injury and damage from this research project through the fault of the University, its officers or employees, you have the right to bring legal action against the University to recover the damage done to you subject to the limitations and conditions of the Oregon Tort Claims Act. You have not waived your legal rights by signing this form. For clarification on this subject, or if you have further questions, please call the Medical Services Director at (503) 494-6020.

Legacy Health System is composed of non-profit hospitals that are dedicated to provide medical treatment for injury or illness. Should you suffer any injury as a result of this research project, emergency medical treatment will be available. However, compensation for emergency medical treatment will be available from the hospital only if you establish that the injury occurred through the fault of the hospital, its physicians, officers or employees. Further information regarding this policy, or questions concerning your rights as a research participant may be obtained from the Office of Research Administration at (503) 413-2474.

PARTICIPATION: Nadine Parker, (503) 494-3840, has offered to answer any other questions you may have about this study. If you have any questions regarding your rights as a research subject, you may contact the Oregon Health Sciences University Institutional Review Board at (503) 494-7887. You may refuse to participate, or you may withdraw from this study at any time without affecting your relationship with or treatment at the Oregon Health Sciences University or Legacy Health Systems. If you do not participate, additional medical care by your physician will still be continued. The final report of the research will be available in the OHSU library in Portland, Oregon. Your signature below indicates that you have read the foregoing and agree to participate in this study.

____

SIGNATURE DATE

Appendix C

Physician Letters of Support Sent to Potential Participants from Oregon Health Sciences University and Legacy Health Systems

OHSU
SCHO
MEDIC

3181 S.W. SAM JACKSON PARK RD. PV-01
PORTLAND, OR 97201-3098
503-494-5674 INFORMATION
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OREGON HEALTH SCIENCES UNIVERSITY

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UNIVERSITY OTOLARYNGOLOGY ASSOCIATES, P.C.
PHYSICIANS AND SURGEONS

This letter is to introduce a study of quality of life for persons who have had surgery for head and neck cancer and their spouses. The researcher, Nadine M. Parker, is a registered nurse studying for her doctoral degree at Oregon Health Sciences University. We are her sponsors here at OHSU.

Please take a few moments to read Mrs. Parker's letter and look at the questionnaires. There is one questionnaire for you and one for your spouse. Her letter explains the study's purposes, the importance of your participation, and issues related to confidentiality and risk. She estimates that each questionnaire could be completed in less than one hour. If you choose to participate in the study, mail your completed questionnaires directly to her in the stamped envelopes she has provided for you. If you do not wish to participate, simply throw the questionnaires away. Your relationship with us will not be affected at all. There will be no record of who does and does not participate.

Thank you for considering participation in the study. The information you provide may assist nurses and doctors to better understand the experiences of patients who have head and neck cancer surgery (and spouses) and provide better care in the future.

If you have questions about the sponsorship of this study, please contact us at (503) 494-5355. Questions regarding the study itself should be directed to Nadine Parker.

Sincerely,

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Associate Professor Otolaryngology/Head and Neck Surgery
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(Date)

Dear

This letter is to introduce a study of quality of life for persons who have had surgery for head and neck cancer and their spouses. The researcher, Nadine M. Parker, is a registered nurse studying for her doctoral degree at Oregon Health Sciences University. We are her sponsors here at Legacy Health System.

Please take a few moments to read Mrs. Parker's letter and look at the questionnaires. There is one questionnaire for you and one for your spouse. Her letter explains the study's purposes, the importance of your participation, and issues related to confidentiality and risk. She estimates that each questionnaire could be completed in less than one hour. If you choose to participate in the study, mail your completed questionnaires directly to her in the stamped envelopes she has provided for you. If you do not wish to participate, simply throw the questionnaires away. Your relationship with us will not be affected at all. There will be no record of who does and does not participate.

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Sincerely,

Eric J. Dierks, M.D., D.M.D., F.A.C.S.
Bryce E. Potter, M.D., D.M.D., F.A.C.S.
Legacy Health System

Appendix D

Questionnaires for Patients and Spouses

Patient's Questionnaire

Quality of Life in Head and Neck Cancer Patients and Their Spouses

Quality of Life in Head and Neck Cancer Patients and Their Spouses

Purpose: The purpose of this research is to look at what affects quality of life in persons who have had head and neck cancer and their spouses.

Understanding the effects of head and neck cancer on the quality of life of patients and their spouses will help nurses and providers to care for families like yours more effectively. Your answers are especially important to us because nurses and doctors do not have a clear understanding of what life is like after the treatment of head and neck cancer.

Questionnaire Information: This questionnaire should take you less than one hour to complete. You may use either a pen or a pencil. If you wish, you may complete part of the questionnaire, take a break, and complete the questionnaire when you are rested.

Directions are given just before each new set of questions. There are no right or wrong answers to any of the questions.

When you have finished, please mail your completed questionnaire to me in the enclosed self-addressed, stamped envelope. There is one envelope for the patient and one for the spouse.

Although spouses sometimes like to share their answers with each other, for research purposes we would prefer that your answers are private and confidential.

Thank you for sharing your views about the quality of your everyday life with me.

Nadine M. Parker, MS, RN
Doctoral Candidate, School of Nursing
Oregon Health Sciences University, Portland, Oregon
Research advisor's phone number: (503) 494-3840

We would like to improve our estimate of the time it takes to complete this questionnaire.
Please keep track of the time it takes you to complete it.
If you take breaks -- which is fine -- do not count the break time, just the time you are actually working on the questionnaire.

Time you started the questionnaire: ___________

YOUR SATISFACTION WITH LIFE

These 16 items relate to your satisfaction with life. Please circle the one number that best describes your satisfaction for each item.
If an item does not apply to your life, please write "NA" (for "not applicable") next to the question number.

		Delighted	Pleased	Mostly Satisfied	Mixed	Mostly Dissatisfied	Unhappy	Terrible
Q1.	Material comforts: home, food, financial security	7	6	5	4	3	2	1
Q2.	Health: being physically fit and vigorous	7	6	5	4	3	2	1
Q3.	Relationships with parents, siblings & other relatives: communicating, visiting, helping	7	6	5	4	3	2	1
Q4.	Having and rearing children	7	6	5	4	3	2	1
Q5.	Close relations with spouse or significant other	7	6	5	4	3	2	1
Q6.	Close friends	7	6	5	4	3	2	1
Q7.	Helping and encouraging others, volunteering	7	6	5	4	3	2	1
Q8.	Participating in organizations and public affairs	7	6	5	4	3	2	1
Q9.	Learning: attending school, improving knowledge	7	6	5	4	3	2	1
Q10.	Understanding yourself: knowing what life is about	7	6	5	4	3	2	1
Q11.	Work: Job or home	7	6	5	4	3	2	1
Q12.	Expressing yourself creatively	7	6	5	4	3	2	1
Q13.	Socializing: meeting other people, doing things	7	6	5	4	3	2	1
Q14.	Reading, music, or watching entertainment	7	6	5	4	3	2	1
Q15.	Participating in active recreation	7	6	5	4	3	2	1
Q16.	Independence, being able to do things for yourself	7	6	5	4	3	2	1

(Burckhardt, Woods, Schultz, & Ziebarth, 1989)

YOUR VIEW OF LIFE

This set of questions relates to various aspects of your life. Each question has seven possible answers. Please circle the number which best expresses your answer, with numbers 1 and 7 being the extreme answers. If the words under number 1 are right for you, circle 1; if the words under number 7 are right for you, circle 7. If you feel differently, circle the number that best expresses your feeling. Please give only one answer to each question. There are no right or wrong answers.

C1. When you talk to people, do you have the feeling that they don't understand you?

1	2	3	4	5	6	7
Never have this feeling						Always have this feeling

C2. In the past, when you had to do something which depended upon cooperation with others, did you have the feeling that it:

1	2	3	4	5	6	7
Surely wouldn't get done						Surely would get done

C3. Think of the people with whom you come into contact daily, aside from the ones to whom you feel closest. How well do you know most of them?

1	2	3	4	5	6	7
You feel that they're strangers						You know them very well

C4. Do you have the feeling that you don't really care about what goes on around you?

1	2	3	4	5	6	7
Very seldom or never						Very often

C5. Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well?

1	2	3	4	5	6	7
Never happened						Always happened

C6. Has it happened that people whom you counted on disappointed you?

1	2	3	4	5	6	7
Never happened						Always happened

(Antonovsky, 1989)

C7. Life is:

1	2	3	4	5	6	7
Full of interest						Completely routine

C8. Until now your life has had:

1	2	3	4	5	6	7
No clear goals or purpose at all						Very clear goals and purpose

C9. Do you have the feeling you're being treated unfairly?

1	2	3	4	5	6	7
Very often						Very seldom or never

C10. In the past ten years your life has been:

1	2	3	4	5	6	7
Full of changes without your knowing what will happen next						Completely consistent and clear

C11. Most of the things you do in the future will probably be:

1	2	3	4	5	6	7
Completely fascinating						Deadly boring

C12. Do you have the feeling that you are in an unfamiliar situation and don't know what to do?

1	2	3	4	5	6	7
Very often						Very seldom or never

C13. What best describes how you see life:

1	2	3	4	5	6	7
One can always find a solution to painful things in life						There is no solution to painful things in life

C14. When you think about your life, you very often:

1	2	3	4	5	6	7
Feel how good it is to be alive						Ask yourself why you exist at all

C15. When you face a difficult problem, the choice of a solution is:

1	2	3	4	5	6	7
Always confusing and hard to find						Always completely clear

C16. Doing the things you do every day is:

1	2	3	4	5	6	7
A source of deep pleasure and satisfaction						A source of pain and boredom

C17. Your life in the future will probably be:

1	2	3	4	5	6	7
Full of changes without your knowing what will happen next						Completely consistent and clear

C18. When something unpleasant happened in the past your tendency was:

1	2	3	4	5	6	7
"To eat yourself up" about it						To say "OK, that's that, I have to live with it," and go on

C19. Do you have very mixed up feelings and ideas?

1	2	3	4	5	6	7
Very often						Very seldom or never

C20. When you do something that gives you a good feeling:

1	2	3	4	5	6	7
It's certain that you'll go on feeling good						It's certain that something will happen to spoil it

C21. Does it happen that you have feelings inside you would rather not feel?

1	2	3	4	5	6	7
Very often						Very seldom or never

(Antonovsky, 1989)

C22. You anticipate that your personal life in the future will be:

1	2	3	4	5	6	7
Totally without meaning or purpose						Full of meaning and purpose

C23. Do you think that there will always be people whom you'll be able to count on in the future?

1	2	3	4	5	6	7
You're certain there will be						You doubt there will be

C24. Does it happen that you have the feeling that you don't know exactly what's about to happen?

1	2	3	4	5	6	7
Very often						Very seldom or never

C25. Many people--even those with a strong character--sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past?

1	2	3	4	5	6	7
Never						Very often

C26. When something happened, have you generally found that:

1	2	3	4	5	6	7
You overestimated or underestimated its importance						You saw things in the right proportion

C27. When you think of difficulties you are likely to face in important aspects of your life, do you have the feeling that:

1	2	3	4	5	6	7
You will always succeed in overcoming the difficulties						You won't succeed in overcoming the difficulties

C28. How often do you have the feeling that there's little meaning in the things you do in your daily life?

1	2	3	4	5	6	7
Very often						Very seldom or never

C29. How often do you have feelings that you're not sure you can keep under control?

1	2	3	4	5	6	7
Very often						Very seldom or never

YOU AND YOUR SPOUSE

Now we would like you to let us know how you and your spouse feel about each other at the current time.

		Not at all	A little	Some	Quite a bit	A great deal
1.	To what extent do the two of you see eye to eye?	0	1	2	3	4
2.	How close do you feel to him or her?	0	1	2	3	4
3.	How much do you enjoy sharing past experiences with him or her?	0	1	2	3	4
4.	How much does he/she express feelings of appreciation for you and the things you do?	0	1	2	3	4
5.	How attached are you to him/her?	0	1	2	3	4
6.	How much does he/she help you?	0	1	2	3	4
7.	How much do you like to sit and talk with him/her?	0	1	2	3	4
8.	How much love do you feel for him/her?	0	1	2	3	4
9.	To what extent do the two of you share the same values?	0	1	2	3	4
10.	When you really need it, how much does he/she comfort you?	0	1	2	3	4
11.	How much do the two of you laugh together?	0	1	2	3	4
12.	How much do you confide in him/her?	0	1	2	3	4
13.	How much emotional support does he/she give you?	0	1	2	3	4
14.	To what extent do the two of you enjoy the time you spend together?	0	1	2	3	4
15.	How often does he/she express feelings of warmth toward you?	0	1	2	3	4

(Stewart & Archbold, 1986, 1991)

Most people have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your spouse for each item.

	Always Agree	Almost Always Agree	Occasionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
1. Handling family finances	1	2	3	4	5	6
2. Matters of recreation	1	2	3	4	5	6
3. Religious matters	1	2	3	4	5	6
4. Demonstrations of affection	1	2	3	4	5	6
5. Friends	1	2	3	4	5	6
6. Sex relations	1	2	3	4	5	6
7. Conventionality (correct or proper behavior)	1	2	3	4	5	6
8. Philosophy of life	1	2	3	4	5	6
9. Ways of dealing with parents or inlaws	1	2	3	4	5	6
10. Aims, goals, and things believed important	1	2	3	4	5	6
11. Amount of time spent together	1	2	3	4	5	6
12. Making major decisions	1	2	3	4	5	6
13. Household tasks	1	2	3	4	5	6
14. Leisure time interests and activities	1	2	3	4	5	6
15. Career decisions	1	2	3	4	5	6

	All the time	Most of the time	More often than not	Occasionally	Barely	Never
16. How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6
17. How often do you or your mate leave the house after a fight?	1	2	3	4	5	6
18. In general, how often do you think that things between you and your partner are going well?	1	2	3	4	5	6
19. Do you confide in your mate?	1	2	3	4	5	6
20. Do you ever regret that you married?	1	2	3	4	5	6
21. How often do you and your partner quarrel?	1	2	3	4	5	6
22. How often do you and your mate "get on each other's nerves"?	1	2	3	4	5	6

(Spanier, 1976)

	Every day	Almost Every day	Occasionally	Rarely	Never
23. Do you kiss your mate?	5	4	3	2	1
24. Do you and your mate engage in outside interests together?	5	4	3	2	1

How often would you say the following events occur between you and your mate?

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
25. Have a stimulating exchange of ideas	1	2	3	4	5	6
26. Laugh together	1	2	3	4	5	6
27. Calmly discuss something	1	2	3	4	5	6
28. Work together on a project	1	2	3	4	5	6

These are some things about which couples sometimes agree and sometimes disagree. Indicate if either item below caused differences of opinions or were problems in your relationship <u>during the past few weeks</u>. (Circle yes or no)

29. YES NO Being too tired for sex

30. YES NO Not showing love.

31. **The following short statements represent different degrees of happiness in your relationship. The middle choice, "happy", represents the degree of happiness of most relationships. Please circle the choice below which best describes the degree of happiness, all things considered, of your relationship.**

Extremely Unhappy	**Fairly Unhappy**	**A little Unhappy**	**Happy**	**Very Happy**	**Extremely Happy**	**Perfect**

32. **Which of the following statements best describes how you feel about the future of your relationship? (Please check one)**

____I want desperately for my relationship to succeed, and would go to amost any length to see that it does.

____I want very much for my relationship to succeed, and will do all I can to see that it does.

____I want very much for my relationship to succeed, and will do my fair share to see that it does.

____It would be nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed.

____It would be nice if my relationship succeeded, but I refuse to do any more than I am doing now to keep the relationship going.

____My relationship can never succeed, and there is no more that I can do to keep the relationship going.

(Spanier, 1976)

YOUR FEELINGS DURING THE PAST WEEK

Using the scale below, **CIRCLE** the number which best describes how often you felt or behaved this way—**DURING THE PAST WEEK.**

1 = Rarely or none of the time (less than 1 day)
2 = Some or a little of the time (1-2 days)
3 = Occasionally or a moderate amount of time (3-4 days)
4 = Most or all of the time (5-7 days)

DURING THE PAST WEEK:	Rarely or None	Some or A Little	Occasionally or Moderate	Most or All
1. I was bothered by things that usually don't bother me	1	2	3	4
2. I didn't feel like eating; my appetite was poor	1	2	3	4
3. I felt that I could not shake off the blues even with help from my family and friends	1	2	3	4
4. I felt that I was just as good as other people	1	2	3	4
5. I had trouble keeping my mind on what I was doing	1	2	3	4
6. I felt depressed	1	2	3	4
7. I felt that everything I did was an effort	1	2	3	4
8. I felt hopeful about the future	1	2	3	4
9. I thought my life had been a failure	1	2	3	4
10. I felt fearful	1	2	3	4
11. My sleep was restless	1	2	3	4
12. I was happy	1	2	3	4
13. I talked less than usual	1	2	3	4
14. I felt lonely	1	2	3	4
15. People were unfriendly	1	2	3	4
16. I enjoyed life	1	2	3	4
17. I had crying spells	1	2	3	4
18. I felt sad	1	2	3	4
19. I felt that people disliked me	1	2	3	4
20. I could not "get going."	1	2	3	4

(Radloff, 1977)

YOUR FEELINGS ABOUT THE ILLNESS

Please read the statements below and indicate your response to each by circling the number below from 1 (Strongly Disagree) to 5 (Strongly Agree)

	Strongly Disagree	Mildly Disagree	Uncertain	Mildly Agree	Strongly Agree
1. This illness is not as serious as another I've experienced	1	2	3	4	5
2. When you're ill, people pay special attention to your appearance	1	2	3	4	5
3. I have paid attention to the warning signs of serious illness	1	2	3	4	5
4. I don't want people to inquire about my health	1	2	3	4	5
5. I think some aspects of a serious illness are best not discussed	1	2	3	4	5
6. People don't seem to know quite how to react to me since I've been ill	1	2	3	4	5
7. I haven't told people at work about my illness	1	2	3	4	5
8. Since I've been ill some people seem to keep their distance from me	1	2	3	4	5
9. This illness has put a serious strain on my family	1	2	3	4	5
10. I worry that my illness may be contagious	1	2	3	4	5
11. I feel comfortable discussing my illness with my children	1	2	3	4	5
12. I can discuss any aspect of my illness with my spouse	1	2	3	4	5
13. I think people often hide their feelings from me	1	2	3	4	5
14. My family has become especially close since my illness	1	2	3	4	5
15. This illness is the most serious I've experienced	1	2	3	4	5
16. Some people treat me as if my illness were contagious	1	2	3	4	5
17. I am afraid my illness may affect the way people judge my performance at work	1	2	3	4	5
18. I feel comfortable discussing my illness with my close friends	1	2	3	4	5
19. Since I've been ill, people have been especially kind and helpful	1	2	3	4	5

(Stahly, 1988)

		Strongly Disagree	Mildly Disagree	Uncertain	Mildly Agree	Strongly Agree
20	I sometimes feel others blame me for my illness	1	2	3	4	5
21.	My illness hasn't interferred with my job	1	2	3	4	5
22.	There are some aspects of my illness that I really can't discuss with anyone	1	2	3	4	5
23.	Sometimes I feel like my illness is a punishment	1	2	3	4	5
24.	I don't think the cause of my illness is well understood	1	2	3	4	5
25.	I sense others are sometimes embarrassed to ask about my illness	1	2	3	4	5
26.	I would like to see my doctor alone sometimes so I can ask questions that might upset my spouse	1	2	3	4	5
27.	I feel comfortable discussing my illness with casual acquaintances	1	2	3	4	5
28.	I am ashamed to discuss my illness	1	2	3	4	5
29.	Talking about serious illness may be tempting fate	1	2	3	4	5
30.	Since my illness I find I must often "break the ice" on social occasions to put others at ease	1	2	3	4	5
31.	Although my chances of recovery are good, some friends treat me as if I were dying	1	2	3	4	5
32.	I wear special clothes and/or makeup so the effects of the illness won't be noticed by others	1	2	3	4	5
33.	There are questions I would like to ask my doctor but I am reluctant to ask	1	2	3	4	5
34.	I am embarrassed by my illness.....................................	1	2	3	4	5
35.	Some people seem to feel that if they think too much about my illness they may get it too	1	2	3	4	5
36.	I think a lot about my appearance since I've been ill	1	2	3	4	5
37.	Some people I know seem to believe it's bad luck to talk about illness	1	2	3	4	5
38.	I am always careful to take medications as they are prescribed	1	2	3	4	5

(Stahly, 1988)

YOUR LIFE SINCE THIS ILLNESS

Following is a list of 9 items that other people with your illness have said are important. For each item please indicate the severity of problems associated with that item <u>during the past 7 days</u> by circling the number below each item that corresponds to the statement that most accurately describes your experience. <u>Please circle one response for each item</u>.

1. <u>Pain</u>

5 I have no pain.
4 There is mild pain not needing medication.
3 I have moderate pain--requires regular medication (codeine or non-narcotic).
2 I have severe pain controlled only by narcotics.
1 I have severe pain not controlled by medication.

2. <u>Disfigurement</u>

5 There is no change in my appearance.
4 The change in my appearance is minor.
3 My appearance bothers me but I remain active.
2 I feel significantly disfigured and limit my activities due to my appearance.
1 I cannot be with people due to my appearance.

3. <u>Activity</u>

5 I am as active as I have ever been.
4 There are times when I can't keep up my old pace, but not often.
3 I am often tired and have slowed down my activites although I still get out.
2 I don't go out because I don't have the strength.
1 I am usually in bed or a chair and don't leave home.

4. <u>Recreation/entertainment</u>

5 There are no limitations to recreation at home and away from home.
4 There are a few things I can't do but I still get out and enjoy life.
3 There are many times when I wish I could get out more but I'm not up to it.
2 There are severe limitations to what I can do; mostly I stay at home and watch TV.
1 I can't do anything enjoyable.

(Hassan & Weymuller, 1993)

Please circle one response for each item.

5. **Employment**
   - 5 I work full time.
   - 4 I have a part-time but permanent job.
   - 3 I only have occasional employment.
   - 2 I am retired (check one below).
     - ____Not related to cancer treatment.
     - ____Due to cancer treatment.
   - 1 I am unemployed.

6. **Chewing**
   - 3 I can chew as well as ever.
   - 2 I can eat soft solids but cannot chew some foods.
   - 1 I cannot even chew soft solids.

7. **Swallowing**
   - 4 I can swallow as well as ever.
   - 3 I cannot swallow certain solid foods.
   - 2 I can only swallow liquid food.
   - 1 I cannot swallow because it "goes down the wrong way" and chokes me.

8. **Speech**
   - 4 My speech is the same as always.
   - 3 I have difficulty with saying some words but I can be understood over the phone.
   - 2 Only my family and friends can understand me.
   - 1 I cannot be understood.

9. **Shoulder disability**
   - 4 I have no problem with my shoulder.
   - 3 My shoulder is stiff but it has not affected my activity or strength.
   - 2 Pain or weakness in my shoulder has caused me to change my work.
   - 1 I cannot work due to problems with my shoulder.

TELL US ABOUT YOU

1. In what year were you born? 19_____

2. Are you female or male?

Female	1
Male	2

3. What is your race?

African American	1
Asian or Pacific Islander	2
Hispanic	3
Native American	4
White	5
Other	6

If other, write in___________________

4. What is your current marital status?

Married	1
Widowed	2
Divorced	3
Separated	4
Other	6

5. If currently married, HOW MANY YEARS?_________

6. What is the highest grade in school that you completed?

Completed 6th grade or less	7
Junior high school (7th - 9th grade)	6
Partial high school (10th - 11th grade)	5
High school graduate	4
Partial college training	3
Completed college	2
Graduate professional training	1

7. What kind of work have you done most of your working life?______________________________

____

8. In general, would you say your health is (Circle One Number):

Excellent	5
Very Good	4
Good	3
Fair	2
Poor	1

9. Has your cancer come back since the first surgery? **YES** **NO**

10. Are you completely cured of cancer at the present time? **YES** **NO**

11. Do you currently have a tracheostomy (a tube in the neck for breathing)? **YES** **NO**

12. Do you currently have a gastrostomy tube (a tube directly into the stomach for liquid feedings)? **YES** **NO**

13. Are you currently on chemotherapy? **YES** **NO**

14. Thinking of your experience, what has been the most difficult part for you? ____________________

____

____

15. What has been the most helpful for you during this experience? ____________________

____

____

16. What advice would you give others who are about to go through an experience similar to yours? ____

____

____

How long did it take you to complete this questionnaire? __________ minutes

Thank you very much for completing this survey. Would you take a few more minutes to give us your candid reactions to the survey? (Please CIRCLE your answer)

1. How interesting or boring was this survey?
    1 Very interesting
    2 Pretty interesting
    3 Somewhat interesting and somewhat boring
    4 Pretty boring
    5 Very boring

2. Were the questions on this survey clear or confusing?
    1 Everything was very clear
    2 Most questions were clear; only a few were confusing
    3 Some questions were clear and some were confusing
    4 Only a few questions were clear; most were confusing
    5 Nearly all the questions were confusing

    What question or page of questions was most confusing to you? ____________________

3. Were any of the questions in general emotionally upsetting to you?

1 Not at all	3 Some
2 A little	4 A lot

What question or page of questions was most emotionally upsetting to you? ____________________

Please complete the following sentences:

The thing I liked <u>most</u> about this survey was: ____________________

The thing I liked <u>least</u> about this survey was: ____________________

Please use the space below if there is any other information that you would like to tell me or you think I should know about the quality of your life since surgery.

Thank you very much for completing this questionnaire! New information provided by those who complete this survey will help us understand more about the life quality of patients who have had surgery for head and neck cancer and their spouses. If you have misplaced the return envelope or have questions regarding this questionnaire, my address and my research advisor's telephone number follow. *Again, your participation in this research study is greatly appreciated!*

Nadine M. Parker, MS, RN
Oregon Health Sciences University
School of Nursing, Mail Code: SN-ORD
3181 S.W. Sam Jackson Park Road
Portland, Oregon 97201-3098
Telephone for research advisor, Dr. Patricia Archbold: (503) 494-3840

Spouse's Questionnaire

Quality of Life
in Head and Neck Cancer Patients
and Their Spouses

Quality of Life in Head and Neck Cancer Patients and Their Spouses

Purpose: The purpose of this research is to look at what affects quality of life in persons who have had head and neck cancer and their spouses.

Understanding the effects of head and neck cancer on the quality of life of patients and their spouses will help nurses and providers to care for families like yours more effectively. Your answers are especially important to us because nurses and doctors do not have a clear understanding of what life is like after the treatment of head and neck cancer.

Questionnaire Information: This questionnaire should take you less than one hour to complete. You may use either a pen or a pencil. If you wish, you may complete part of the questionnaire, take a break, and complete the questionnaire when you are rested.

Directions are given just before each new set of questions. There are no right or wrong answers to any of the questions.

When you have finished, please mail your completed questionnaire to me in the enclosed self-addressed, stamped envelope. There is one envelope for the patient and one for the spouse.

Although spouses sometimes like to share their answers with each other, for research purposes we would prefer that your answers are private and confidential.

Thank you for sharing your views about the quality of your everyday life with me.

Nadine M. Parker, MS, RN
Doctoral Candidate, School of Nursing
Oregon Health Sciences University, Portland, Oregon
Research advisor's phone number: (503) 494-3840

We would like to improve our estimate of the time it takes to complete this questionnaire.
Please keep track of the time it takes you to complete it.
If you take breaks -- which is fine -- do not count the break time, just the time you are actually working on the questionnaire.

Time you started the questionnaire: ___________

YOUR SATISFACTION WITH LIFE

These 16 items relate to your satisfaction with life. Please circle the one number that best describes your satisfaction for each item.
If an item does not apply to your life, please write "NA" (for "not applicable") next to the question number.

	Delighted	Pleased	Mostly Satisfied	Mixed	Mostly Dissatisfied	Unhappy	Terrible
Q1. Material comforts: home, food, financial security	7	6	5	4	3	2	1
Q2. Health: being physically fit and vigorous	7	6	5	4	3	2	1
Q3. Relationships with parents, siblings & other relatives: communicating, visiting, helping	7	6	5	4	3	2	1
Q4. Having and rearing children	7	6	5	4	3	2	1
Q5. Close relations with spouse or significant other	7	6	5	4	3	2	1
Q6. Close friends	7	6	5	4	3	2	1
Q7. Helping and encouraging others, volunteering	7	6	5	4	3	2	1
Q8. Participating in organizations and public affairs	7	6	5	4	3	2	1
Q9. Learning: attending school, improving knowledge	7	6	5	4	3	2	1
Q10. Understanding yourself: knowing what life is about	7	6	5	4	3	2	1
Q11. Work: Job or home	7	6	5	4	3	2	1
Q12. Expressing yourself creatively	7	6	5	4	3	2	1
Q13. Socializing: meeting other people, doing things	7	6	5	4	3	2	1
Q14. Reading, music, or watching entertainment	7	6	5	4	3	2	1
Q15. Participating in active recreation	7	6	5	4	3	2	1
Q16. Independence, being able to do things for yourself	7	6	5	4	3	2	1

(Burckhardt, Woods, Schultz, & Ziebarth, 1989)

YOUR VIEW OF LIFE

This set of questions relates to various aspects of your life. Each question has seven possible answers. Please circle the number which best expresses your answer, with numbers 1 and 7 being the extreme answers. If the words under number 1 are right for you, circle 1; if the words under number 7 are right for you, circle 7. If you feel differently, circle the number that best expresses your feeling. Please give only one answer to each question. There are no right or wrong answers.

C1. When you talk to people, do you have the feeling that they don't understand you?

1	2	3	4	5	6	7
Never have this feeling						Always have this feeling

C2. In the past, when you had to do something which depended upon cooperation with others, did you have the feeling that it:

1	2	3	4	5	6	7
Surely wouldn't get done						Surely would get done

C3. Think of the people with whom you come into contact daily, aside from the ones to whom you feel closest. How well do you know most of them?

1	2	3	4	5	6	7
You feel that they're strangers						You know them very well

C4. Do you have the feeling that you don't really care about what goes on around you?

1	2	3	4	5	6	7
Very seldom or never						Very often

C5. Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well?

1	2	3	4	5	6	7
Never happened						Always happened

C6. Has it happened that people whom you counted on disappointed you?

1	2	3	4	5	6	7
Never happened						Always happened

(Antonovsky, 1989)

C7. Life is:

1	2	3	4	5	6	7
Full of interest						Completely routine

C8. Until now your life has had:

1	2	3	4	5	6	7
No clear goals or purpose at all						Very clear goals and purpose

C9. Do you have the feeling you're being treated unfairly?

1	2	3	4	5	6	7
Very often						Very seldom or never

C10. In the past ten years your life has been:

1	2	3	4	5	6	7
Full of changes without your knowing what will happen next						Completely consistent and clear

C11. Most of the things you do in the future will probably be:

1	2	3	4	5	6	7
Completely fascinating						Deadly boring

C12. Do you have the feeling that you are in an unfamiliar situation and don't know what to do?

1	2	3	4	5	6	7
Very often						Very seldom or never

C13. What best describes how you see life:

1	2	3	4	5	6	7
One can always find a solution to painful things in life						There is no solution to painful things in life

C14. When you think about your life, you very often:

1	2	3	4	5	6	7
Feel how good it is to be alive						Ask yourself why you exist at all

C15. When you face a difficult problem, the choice of a solution is:

1	2	3	4	5	6	7
Always confusing and hard to find						Always completely clear

C16. Doing the things you do every day is:

1	2	3	4	5	6	7
A source of deep pleasure and satisfaction						A source of pain and boredom

C17. Your life in the future will probably be:

1	2	3	4	5	6	7
Full of changes without your knowing what will happen next						Completely consistent and clear

C18. When something unpleasant happened in the past your tendency was:

1	2	3	4	5	6	7
"To eat yourself up" about it						To say "OK, that's that, I have to live with it," and go on

C19. Do you have very mixed up feelings and ideas?

1	2	3	4	5	6	7
Very often						Very seldom or never

C20. When you do something that gives you a good feeling:

1	2	3	4	5	6	7
It's certain that you'll go on feeling good						It's certain that something will happen to spoil it

C21. Does it happen that you have feelings inside you would rather not feel?

1	2	3	4	5	6	7
Very often						Very seldom or never

C22. You anticipate that your personal life in the future will be:

1	2	3	4	5	6	7
Totally without meaning or purpose						Full of meaning and purpose

C23. Do you think that there will always be people whom you'll be able to count on in the future?

1	2	3	4	5	6	7
You're certain there will be						You doubt there will be

C24. Does it happen that you have the feeling that you don't know exactly what's about to happen?

1	2	3	4	5	6	7
Very often						Very seldom or never

C25. Many people--even those with a strong character--sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past?

1	2	3	4	5	6	7
Never						Very often

C26. When something happened, have you generally found that:

1	2	3	4	5	6	7
You overestimated or underestimated its importance						You saw things in the right proportion

C27. When you think of difficulties you are likely to face in important aspects of your life, do you have the feeling that:

1	2	3	4	5	6	7
You will always succeed in overcoming the difficulties						You won't succeed in overcoming the difficulties

C28. How often do you have the feeling that there's little meaning in the things you do in your daily life?

1	2	3	4	5	6	7
Very often						Very seldom or never

C29. How often do you have feelings that you're not sure you can keep under control?

1	2	3	4	5	6	7
Very often						Very seldom or never

YOU AND YOUR SPOUSE

Now we would like you to let us know how you and your spouse feel about each other at the current time.

	Not at all	A little	Some	Quite a bit	A great deal
1. To what extent do the two of you see eye to eye?	0	1	2	3	4
2. How close do you feel to him or her?	0	1	2	3	4
3. How much do you enjoy sharing past experiences with him or her?	0	1	2	3	4
4. How much does he/she express feelings of appreciation for you and the things you do?	0	1	2	3	4
5. How attached are you to him/her?	0	1	2	3	4
6. How much does he/she help you?	0	1	2	3	4
7. How much do you like to sit and talk with him/her?	0	1	2	3	4
8. How much love do you feel for him/her?	0	1	2	3	4
9. To what extent do the two of you share the same values?	0	1	2	3	4
10. When you really need it, how much does he/she comfort you?	0	1	2	3	4
11. How much do the two of you laugh together?	0	1	2	3	4
12. How much do you confide in him/her?	0	1	2	3	4
13. How much emotional support does he/she give you?	0	1	2	3	4
14. To what extent do the two of you enjoy the time you spend together?	0	1	2	3	4
15. How often does he/she express feelings of warmth toward you?	0	1	2	3	4

(Stewart & Archbold, 1986, 1991)

Most people have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your spouse for each item.

		Always Agree	Almost Always Agree	Occasionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
1.	Handling family finances	1	2	3	4	5	6
2.	Matters of recreation	1	2	3	4	5	6
3.	Religious matters	1	2	3	4	5	6
4.	Demonstrations of affection	1	2	3	4	5	6
5.	Friends	1	2	3	4	5	6
6.	Sex relations	1	2	3	4	5	6
7.	Conventionality (correct or proper behavior)	1	2	3	4	5	6
8.	Philosophy of life	1	2	3	4	5	6
9.	Ways of dealing with parents or inlaws	1	2	3	4	5	6
10.	Aims, goals, and things believed important	1	2	3	4	5	6
11.	Amount of time spent together	1	2	3	4	5	6
12.	Making major decisions	1	2	3	4	5	6
13.	Household tasks	1	2	3	4	5	6
14.	Leisure time interests and activities	1	2	3	4	5	6
15.	Career decisions	1	2	3	4	5	6

		All the time	Most of the time	More often than not	Occasionally	Rarely	Never
16.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?	1	2	3	4	5	6
17.	How often do you or your mate leave the house after a fight?	1	2	3	4	5	6
18.	In general, how often do you think that things between you and your partner are going well?	1	2	3	4	5	6
19.	Do you confide in your mate?	1	2	3	4	5	6
20.	Do you ever regret that you married?	1	2	3	4	5	6
21.	How often do you and your partner quarrel?	1	2	3	4	5	6
22.	How often do you and your mate "get on each other's nerves"?	1	2	3	4	5	6

(Spanier, 1976)

	Every day	Almost Every day	Occasionally	Rarely	Never
23. Do you kiss your mate?	5	4	3	2	1
24. Do you and your mate engage in outside interests together?	5	4	3	2	1

How often would you say the following events occur between you and your mate?

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
25. Have a stimulating exchange of ideas-	1	2	3	4	5	6
26. Laugh together	1	2	3	4	5	6
27. Calmly discuss something	1	2	3	4	5	6
28. Work together on a project	1	2	3	4	5	6

These are some things about which couples sometimes agree and sometimes disagree. Indicate if either item below caused differences of opinions or were problems in your relationship <u>during the past few weeks</u>. (Circle yes or no)

29. YES NO Being too tired for sex

30. YES NO Not showing love.

31. The following short statements represent different degrees of happiness in your relationship. The middle choice, "happy", represents the degree of happiness of most relationships. Please circle the choice below which best describes the degree of happiness, all things considered, of your relationship.

Extremely Unhappy	Fairly Unhappy	A little Unhappy	Happy	Very Happy	Extremely Happy	Perfect

32. Which of the following statements best describes how you feel about the future of your relationship? (Please check one)

____I want desperately for my relationship to succeed, and would go to amost any length to see that it does.

____I want very much for my relationship to succeed, and will do all I can to see that it does.

____I want very much for my relationship to succeed, and will do my fair share to see that it does.

____It would be nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed.

____It would be nice if my relationship succeeded, but I refuse to do any more than I am doing now to keep the relationship going.

____My relationship can never succeed, and there is no more that I can do to keep the relationship going.

(Spanier, 1976)

YOUR FEELINGS DURING THE PAST WEEK

Using the scale below, **CIRCLE** the number which best describes how often you felt or behaved this way—**DURING THE PAST WEEK.**

1 = Rarely or none of the time (less than 1 day)
2 = Some or a little of the time (1-2 days)
3 = Occasionally or a moderate amount of time (3-4 days)
4 = Most or all of the time (5-7 days)

DURING THE PAST WEEK:	Rarely or None	Some or A Little	Occasionally or Moderate	Most or All
1. I was bothered by things that usually don't bother me	1	2	3	4
2. I didn't feel like eating; my appetite was poor	1	2	3	4
3. I felt that I could not shake off the blues even with help from my family and friends	1	2	3	4
4. I felt that I was just as good as other people	1	2	3	4
5. I had trouble keeping my mind on what I was doing	1	2	3	4
6. I felt depressed	1	2	3	4
7. I felt that everything I did was an effort	1	2	3	4
8. I felt hopeful about the future	1	2	3	4
9. I thought my life had been a failure	1	2	3	4
10. I felt fearful	1	2	3	4
11. My sleep was restless	1	2	3	4
12. I was happy	1	2	3	4
13. I talked less than usual	1	2	3	4
14. I felt lonely	1	2	3	4
15. People were unfriendly	1	2	3	4
16. I enjoyed life	1	2	3	4
17. I had crying spells	1	2	3	4
18. I felt sad	1	2	3	4
19. I felt that people disliked me	1	2	3	4
20. I could not "get going."	1	2	3	4

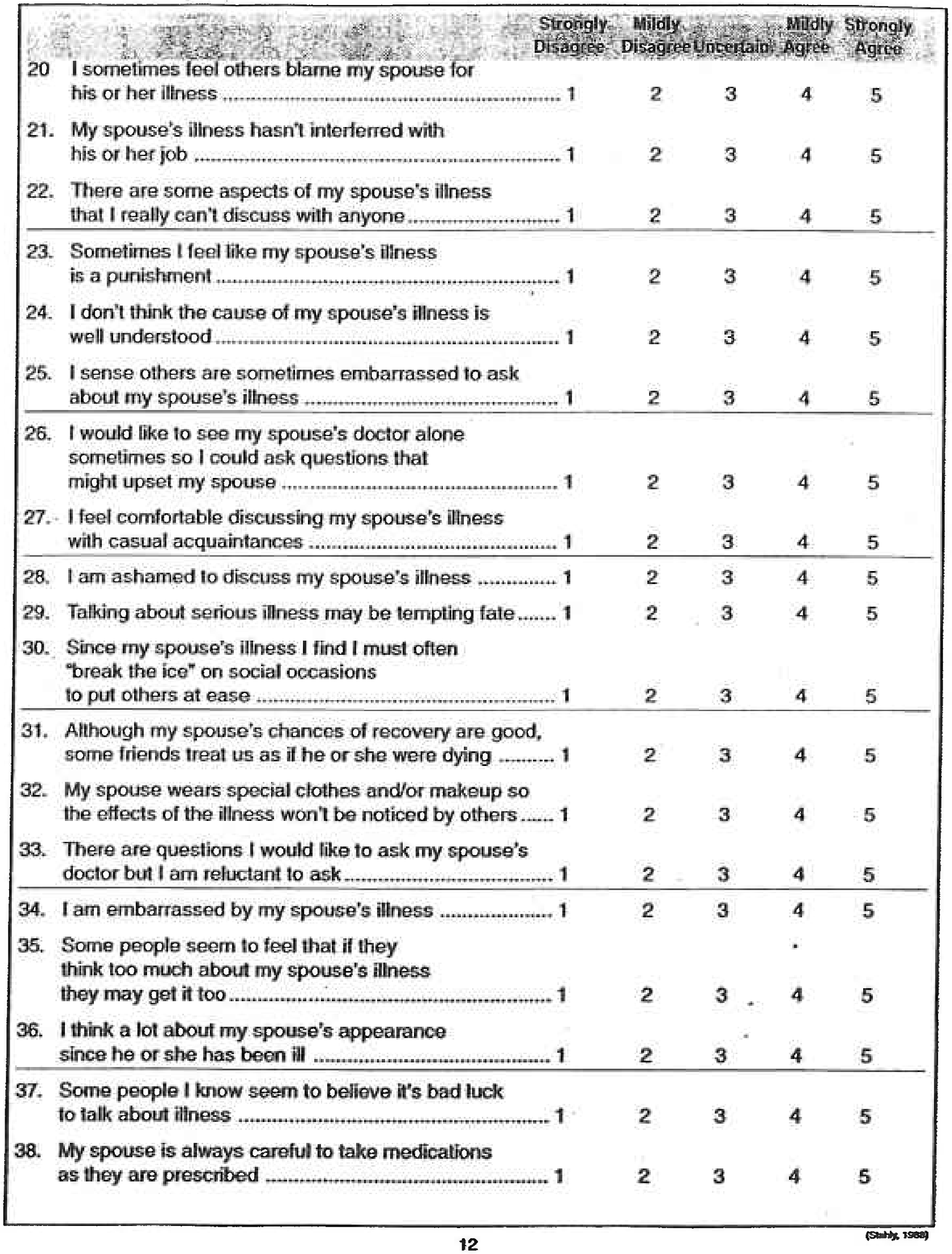
(Radloff, 1977)

YOUR FEELINGS ABOUT YOUR SPOUSE'S ILLNESS

Please read the statements below and indicate your response to each by circling the number below from 1 (Strongly Disagree) to 5 (Strongly Agree)

	Strongly Disagree	Mildly Disagree	Uncertain	Mildly Agree	Strongly Agree
1. This illness is not as serious as another my spouse has experienced	1	2	3	4	5
2. When you're ill, people pay special attention to your appearance	1	2	3	4	5
3. We have paid attention to the warning signs of serious illness	1	2	3	4	5
4. I don't want people to inquire about my spouse's health	1	2	3	4	5
5. I think some aspects of a serious illness are best not discussed	1	2	3	4	5
6. People don't seem to know quite how to react to my spouse since he or she has been ill	1	2	3	4	5
7. I haven't told people at work about my spouse's illness	1	2	3	4	5
8. Since my spouse has been ill some people seem to keep their distance from him or her	1	2	3	4	5
9. This illness has put a serious strain on our family	1	2	3	4	5
10. I worry that my spouse's illness may be contagious	1	2	3	4	5
11. I feel comfortable discussing my spouse's illness with my children	1	2	3	4	5
12. I can discuss any aspect of my spouse's illness with him or her	1	2	3	4	5
13. I think people often hide their feelings from my spouse and me	1	2	3	4	5
14. Our family has become especially close since my spouse's illness	1	2	3	4	5
15. This illness is the most serious we've experienced	1	2	3	4	5
16. Some people treat us as if my spouse's illness were contagious	1	2	3	4	5
17. I am afraid my spouse's illness may affect the way people judge his or her performance at work	1	2	3	4	5
18. I feel comfortable discussing my spouse's illness with my close friends	1	2	3	4	5
19. Since my spouse has been ill, people have been especially kind and helpful	1	2	3	4	5

(Stahly, 1988)



	Strongly Disagree	Mildly Disagree	Uncertain	Mildly Agree	Strongly Agree
20 I sometimes feel others blame my spouse for his or her illness	1	2	3	4	5
21. My spouse's illness hasn't interferred with his or her job	1	2	3	4	5
22. There are some aspects of my spouse's illness that I really can't discuss with anyone	1	2	3	4	5
23. Sometimes I feel like my spouse's illness is a punishment	1	2	3	4	5
24. I don't think the cause of my spouse's illness is well understood	1	2	3	4	5
25. I sense others are sometimes embarrassed to ask about my spouse's illness	1	2	3	4	5
26. I would like to see my spouse's doctor alone sometimes so I could ask questions that might upset my spouse	1	2	3	4	5
27. I feel comfortable discussing my spouse's illness with casual acquaintances	1	2	3	4	5
28. I am ashamed to discuss my spouse's illness	1	2	3	4	5
29. Talking about serious illness may be tempting fate	1	2	3	4	5
30. Since my spouse's illness I find I must often "break the ice" on social occasions to put others at ease	1	2	3	4	5
31. Although my spouse's chances of recovery are good, some friends treat us as if he or she were dying	1	2	3	4	5
32. My spouse wears special clothes and/or makeup so the effects of the illness won't be noticed by others	1	2	3	4	5
33. There are questions I would like to ask my spouse's doctor but I am reluctant to ask	1	2	3	4	5
34. I am embarrassed by my spouse's illness	1	2	3	4	5
35. Some people seem to feel that if they think too much about my spouse's illness they may get it too	1	2	3	4	5
36. I think a lot about my spouse's appearance since he or she has been ill	1	2	3	4	5
37. Some people I know seem to believe it's bad luck to talk about illness	1	2	3	4	5
38. My spouse is always careful to take medications as they are prescribed	1	2	3	4	5

12

(Stahly, 1988)

TELL US ABOUT YOU

1. In what year were you born? 19_____

2. Are you female or male?

    Female 1
    Male 2

3. What is your race?

    African American 1
    Asian or Pacific Islander 2
    Hispanic 3
    Native American 4
    White 5
    Other 6
    If other, write in__________________

4. What is your current marital status?

    Married 1
    Widowed 2
    Divorced 3
    Separated 4
    Other 6

5. If currently married, HOW MANY YEARS?_________

6. What is the highest grade in school that you completed?

    Completed 6th grade or less 7
    Junior high school (7th - 9th grade) 6
    Partial high school (10th - 11th grade) 5
    High school graduate 4
    Partial college training 3
    Completed college 2
    Graduate professional training 1

7. What kind of work have you done most of your working life?______________________________

    ____

8. In general, would you say YOUR health is (Circle One Number):

    Excellent 5
    Very Good 4
    Good 3
    Fair 2
    Poor 1

9. What is the total amount of your yearly household income? Please include money from jobs, net income from a business or farm, dividends, interest, net income from rent, social security, and any other money income.

Under $5,000	1
$5,000 - $9,999	2
$10,000 - $19,000	3
$20,000 - $29,999	4
$30,000 - $39,999	5
$40,000 - 49,999	6
$50,000 - $74,999	7
$75,000 - $99,000	8
$100,000 or more	9

10. Has your spouse's cancer come back since the first surgery? **YES** **NO**

11. Is your spouse completely cured of cancer at the present time? **YES** **NO**

12. Does your spouse currently have a tracheostomy (a tube in the neck for breathing)? **YES** **NO**

13. Does your spouse currently have a gastrostomy tube (a tube directly into the stomach for liquid feedings)? **YES** **NO**

14. Is your spouse currently on chemotherapy? **YES** **NO**

15. Thinking of your experience, what has been the most difficult part for you? ____________________

16. What has been the most helpful for you during this experience? ____________________

17. What advice would you give others who are about to go through an experience similar to yours? ____________________

How long did it take you to complete this questionnaire? _________ minutes

Thank you very much for completing this survey. Would you take a few more minutes to give us your candid reactions to the survey? (Please CIRCLE your answer)

1. How interesting or boring was this survey?
    1 Very interesting
    2 Pretty interesting
    3 Somewhat interesting and somewhat boring
    4 Pretty boring
    5 Very boring

2. Were the questions on this survey clear or confusing?
    1 Everything was very clear
    2 Most questions were clear; only a few were confusing
    3 Some questions were clear and some were confusing
    4 Only a few questions were clear; most were confusing
    5 Nearly all the questions were confusing

    What question or page of questions was most confusing to you? ______________________

3. Were any of the questions in general emotionally upsetting to you?
    1 Not at all
    2 A little
    3 Some
    4 A lot

    What question or page of questions was most emotionally upsetting to you? ______________

Please complete the following sentences:

The thing I liked <u>most</u> about this survey was: ______________________

The thing I liked <u>least</u> about this survey was: ______________________

Please use the space below if there is any other information that you would like to tell me or you think I should know about the quality of your life since surgery.

Thank you very much for completing this questionnaire! New information provided by those who complete this survey will help us understand more about the life quality of patients who have had surgery for head and neck cancer and their spouses. If you have misplaced the return envelope or have questions regarding this questionnaire, my address and my research advisor's telephone number follow. *Again, your participation in this research study is greatly appreciated!*

Nadine M. Parker, MS, RN
Oregon Health Sciences University
School of Nursing, Mail Code: SN-ORD
3181 S.W. Sam Jackson Park Road
Portland, Oregon 97201-3098
Telephone for research advisor, Dr. Patricia Archbold: (503) 494-3840

Appendix E

Postcard Follow-up Sent One Week After Initial Mailing

Dear Sir/Madam:

One week ago I mailed a questionnaire to you and your spouse about quality of life in patients with head and neck cancer and their spouses. If you have already completed and returned them to me, please accept my sincere thanks. If not, please do so today. Because the questionnaires have only been sent to a small sample, it is very important that your comments are included in the results. If by some chance you did not receive the questionnaire, do not be concerned. In one week another questionnaire will be mailed to you and another for your spouse.

Sincerely,

Nadine M. Parker, MS, RN
Doctoral Student, School of Nursing
Oregon Health Sciences University, Portland, OR

Appendix F

Letter of Thanks to Participants

Dear (Names):

I received your completed "Quality of Life in Head and Neck Cancer Patients and Their Spouses" questionnaires. Thank you for the completion of the questionnaires. I appreciate your efforts and the time that you took to complete the questionnaires.

The information you provided will assist nurses and doctors to better understand the effects of surgery and radiation treatment on quality of life and your relationship with your family members.

By participating in this study, you may have contributed information that will benefit other patients and their spouses in the future. Again, thank you for your participation.

Sincerely,

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Appendix G

Summary of Proposal, Implemented Changes, and Explanations of Modifications

Summary of Proposal, Implemented Changes, and Explanations of Modification.

	Proposed	Actual Implementation	Explanation of Modification
Aims	Two major aims initially guided the study. 1. To examine the relative importance of illness-related, patient, and dyadic variables in explaining quality of life as an outcome for the head and neck cancer patient. The hypotheses related to Aim 1 are that three sets of variables (illness-related, patient, and dyadic) will each contribute significantly to the explained variance in quality of life for the patient. 2. To examine the relative importance of illness-related, spouse, and dyadic variables in explaining quality of life as an outcome for the head and neck cancer spouse. The hypotheses related to Aim 2 are that three sets of variables (illness-related, spouse, and dyadic) will each contribute significantly to the explained variance in quality of life for the spouse.	A third Aim was added: To describe the level and pattern of quality of life and stigma reported by head and neck cancer patients and their spouses. This third Aim was named Aim 1. The former Aim 1 was renamed Aim 2.	The third Aim was added to evaluate means, standard deviations and % of the most frequent patients' and spouses' reported responses on the Global QOL Scale, the UW-QOL Scale and the Stigma Inventory.

	Proposed	Actual Implementation	Explanation of Modification
Methods design	Descriptive, correlational, cross-sectional design. Measures were obtained at one point in time during the first 6 years after initial surgery for head and neck cancer.	A pilot study was implemented. A sample of 11 individuals was recruited who were considered to be experts in the experience of head and neck cancer. Survey packets were mailed to the volunteers and were returned by mail. After evaluating the comments from the experts, it was determined that no changes in the questionnaires would be necessary. Descriptive, correlational, cross-sectional study proceeded as proposed.	This pilot study was done to evaluate the questionnaires in terms of their feasibility (length, readability, understandability) with head and neck cancer patients and their spouses.

	Proposed	Actual Implementation	Explanation of Modification
setting	The study was conducted at 2 large metropolitan institutions. Authorization was granted to obtain access to participants' names from the Tumor Registries of the 2 institutions and review hospital and clinic chart records.	Proceeded as proposed	
sampling	Tumor Registries of 2 metropolitan institutions created a list of cancer patients who met inclusion criteria: (a) 50 years of age or older, (b) currently married, (c) had stage II, III, or IV head or neck cancer at the time of diagnosis, and (d) had initial surgery within the past 6 years. Both spouses needed to be able to read and write English.	Proceeded as proposed	

	Proposed	Actual Implementation	Explanation of Modification
instruments	Because no revisions were made as a result of the pilot study, the instruments described in this chapter were utilized.	A subscale of the Stigma Inventory was used rather than the entire instrument (subscale1: Social Presentation and Social Interaction).	Internal consistency reliability for the Stigma Inventory was examined. Consideration was given to these issues: (a) there were numerous corrected item correlations that were either close to zero or negative, (b) the items on subscale 1 most closely reflect the theory of stigma as explained by Goffman (1963) Internal consistency for both patients and spouses was higher for subscale 1 than for subscales 2, 3 or 4. Subscale 3 did not appear to fit the definition of stigma. Subscales 2 and 4 had acceptable Cronbach's alphas, but there was a restriction of range on the spouses' means for those subscales. A decision was made to retain only the items that most closely represented stigma on subscale 1 for the analysis.
		A new variable (treatment intensity) was created to replace the radiation variable.	This new variable (treatment intensity) was created to differentiate the type of treatment the patients received (surgery alone; surgery and radiation OR chemotherapy; or surgery, surgery and radiation and chemotherapy).
		One item was removed on the University of Washington Quality of Life Scale (item 5: Employment).	Item 5 (Employment) was removed on the University of Washington Quality of Life Scale for the analysis because 26 of the 40 patients in the data set reported that they were retired. In addition, the corrected item total correlations for this item were very low.

	Proposed	Actual Implementation	Explanation of Modification
procedure–sample access	One of the criteria for inclusion included individuals who had been diagnosed within the first 5 years after initial surgery for head and neck cancer.	Individuals were included who had been diagnosed within the first 6 years after initial surgery for head and neck cancer.	The sorting process of the Tumor Registry at one of the sites inadvertently included 10 individuals who had been diagnosed with head and neck cancer up to 6.1 years prior to the study. They were also included.
procedure–mailing questionnaires	A packet was sent to all eligible patients (125 patients met the inclusion criteria) and their spouses containing (a) a cover letter explaining the study addressed to the patient and his/her spouse (Appendix A), (b) a consent form (one for the patient and one for the spouse) (Appendix B), (c) a letter of support for the study from the physicians who performed the surgeries (Appendix C), and (d) a copy of the questionnaires; one for the patient and one for the spouse (Appendix D). One week after the initial mailing, a follow-up postcard was sent to patients and spouses reminding them of the importance of their participation (Appendix E). Thank you letters were mailed to those who responded (Appendix F).	The procedure for mailing questionnaires proceeded as proposed. Nine of the participants sent short notes back stating that their spouse had died. A letter of condolence and thanks was sent to these individuals.	Because there was no provision in the initial proposal to address these responses, a Project Amendment form was drafted and approval was granted by the Internal Review Board to send a letter of condolence and thanks for the 9 individuals who were included in this group.
procedure–consent	Consent was obtained by participants' mailing back the signed consent forms with the completed surveys.	Proceeded as proposed	

	Proposed	Actual Implementation	Explanation of Modification
<u>**Data Analysis**</u>	Quantitative data from self-report questionnaires were analyzed using Pearson's product moment correlation. Pearson's r correlation designates the magnitude and direction of a relationship between two variables (Polit, 1996). Means, standard deviations, skewness and kurtosis were also evaluated for each of the items and the scale totals/averages . Hierarchical multiple regression was used for the analysis to determine which factors contribute significantly to the explained variance in QOL, the outcome variable (Tabachnick & Fidell, 1997). The independent variables (IVs) were entered into the regression equation by blocks. To determine how much a particular variable contributes to the explained variance in QOL, the R^2 increment was evaluated, along with the F change values. The relative contributions of the IVs were determined by looking at the significant beta weights and by observing the signs (+ or -).	Proceeded as proposed, except for the multiple regression analysis. The variables were first entered one at a time.	Because of the small sample size and the need to decrease the number of variables, the variables were individually entered. The goal was to identify variables that were most important in relation to quality of life. The variables that contributed the most to quality of life were retained to identify a more parsimonious model for this sample.

Appendix H

Patients' and Spouses' Qualitative Responses

Patients' Qualitative Responses

1. Thinking of your experience, what has been the most difficult part for you?

01.1 Not being told what the long term effects of the surgery and radiation would be and having to live with those effects.

03.1 I can't get solid food down without drinking water. My tongue won't push my food back far enough.

05.1 Radiation

10.1 Maintaining a positive attitude about the constant fear of cancer returning in the future.

12.1 Fear of recurrence

15.1 It was facing people knowing my talking was very hard to make them understand my wordings.

19.1 The effects of radiation: swallowing, taste, saliva.

21.1 Lack of teeth. Inability to chew and swallow properly.

36.1 Eating–dry mouth–dry foods are especially difficult even with added water–chewing is hard.

37.1 Being away from home for operation and recuperation period in nursing home.

38.1 No ambition

40.1 Dealing with cancer. Not knowing what the next day will bring.

44.1 Getting back to what I consider "feeling normal" to be and not being able to eat many of the foods I used to.

47.1 Eating, chewing and speech

48.1 Fear of operation

49.1 Learning how to talk and eat again

52.1 Not being able to eat solids

54.1 Eating, talking on phone (mouth dries out badly, often have difficulty swallowing).

57.1 Not being able to eat the foods I used to.

61.1 Adjusting

67.1 Inadequate volume for speech

68.1 Learning to eat

69.1 Recovery

70.1 Talking

73.1 The way cancer can and will destroy your body and life without the proper treatment.

77.1 Learning to eat and swallow the way I have to.

81.1 Not being able to talk and breathe

83.1 First 30 days after surgery

85.1 Talking

90.1 Loss of quality of speech

93.1 Hearing–deaf in one ear and very poor hearing in other

99.1 Not being able to eat normally–going out to dinner or friends house for dinner.

104.1 Not being able to eat

107.1 Depression during the first year or so. Knowing that it was more difficult for my wife than for me.

110.1 The pain in the jaw area that I had for two years–also losing two perfect teeth due to abscess caused by surgery.

121.1 No saliva. No teeth.

122.1 Watching other people eat when I can't.

124.1 Eating and swallowing

125.1 Giving up 2 years of a normal life–repeated attempts to bring closure to situation due to failed surgeries.

127.1 I used to be a singer.

2. What has been the most helpful for you during this experience?

01.1 The support group and the sharing of knowledge.

03.1 My surgeon

05.1 Wife

10.1 The Cancer Society. Family and friends.

12.1 Appreciating life–caregivers have been wonderful also

15.1 I finally faced up to the fact that I did have cancer surgery and that I had some serious disfiguring in my face and neck.

19.1 Knowing the progression of cancer has been curtailed

34.1 Positive attitude

36.1 The attitudes. Caring of the Dr.–his helpfulness and understanding

37.1 Love and care by spouse, children and friends

38.1 Friends

40.1 Being able to keep busy–keeps my mind off of problem.

44.1 The consideration, care, and understanding of my condition by friends and acquaintances.

47.1 No answer

48.1 Support and care from daughter, husband, doctors and OHSU staff

49.1 Time

54.1 My husband–preparing soft foods that I can possibly eat.

57.1 Help of family and friends

61.1 My wife

67.1 The tremendous support of my wife and family as well as the medical support staff.

68.1 Advice of therapist and confidence in the doctor

69.1 My wife

73.1 Knowing that I have the support of an outstanding medical staff and the love of my wife, family and friends.

77.1 The people who worked with me on this problem.

81.1 Family support

83.1 Experienced medical staff at OHSU

90.1 Working–staying active

93.1 Strong hearing aid–A wife who has a natural clear and forceful voice

99.1 The Lord God and prayer support from family and friends. Also my wife.

107.1 Support from my wife and those who love me. Confidence in my surgeon. Prayer.

110.1 My doctor's optimism that I would be better. The scars on my neck are barely noticeable.

121.1 Treatments and family

125.1 Family support

127.1 My wife's encouragement–My own determination.

3. What advice would you give others who are about to go through an experience similar to yours?

01.1 Rally all the support and help you can because you are going to need it. Try to find the <u>least</u> drastic means to solve the problem.

03.1 Think positive

05.1 Radiation effects

10.1 See that you get an excellent doctor like the one I had. Dr. D. is by far the very best in the field. Think positive. Take one day at a time.

12.1 Pray a lot–try to talk to others and share your thoughts. I read several inspirational books that helped a great deal.

15.1 Stay in touch with God and He will see you through it all.

19.1 Get the best doctors available and trust them to make the right decisions

34.1 Positive attitude

37.1 Go to the best doctors available

38.1 Go with the flow

40.1 Try chemo first–along with cancer curing drugs. Surgery as a last resort.

44.1 Be positive about your future.

47.1 No advice

48.1 Try to talk to someone who has had the same surgery in advance.

49.1 It has to be done, so do it and have confidence that you will learn to compensate for the after effects.

52.1 Ask more questions than I did and plan more for the future

54.1 Do not expect a fast recovery. IT TAKES TIME! ----so far—FOREVER!!!

57.1 Give it your best shot.

61.1 It beats the hell out of the alternative.

67.1 Resolve your concerns, concentrate on your recovery and rehab, follow the medical advice and be positive.

68.1 Just do it

69.1 Be very patient–recovery can be slower than expected. Don't give up.

70.1 Going to be a big change in your life

73.1 You must remember that when you contract an illness like cancer you will never be the same, but you must fight back with all of your being and with the help of God you will win. If you don't win you gave your all.

77.1 Do everything you are told to do, because in time you will get through this. You learn to adapt.

81.1 Get a hold of my doctors

83.1 Positive thoughts and breakthrough in treatment.

85.1 Hang in there.

90.1 It doesn't have to affect your life as much as you think it will.

93.1 Be cautious about the radiation treatments. Discuss in advance the possibility of additional hearing loss–find foods you can eat to keep weight up.

99.1 If you know the Lord, put your trust in Him. If you don't know the Lord–find Him.

107.1 Have faith and trust and know that it can be cured.

110.1 My surgery was five years ago and except for a small change in my C's and S's I can speak clearly. I feel that Dr. C. did a wonderful job on me–I will always be grateful to him.

121.1 Avoid surgery and radiation–use only as a last choice.

122.1 Do not shun the warmth and friendship of others. You are still the same person.

125.1 Keep your attitude as positive as possible.

127.1 Do as you are told–you'll make it.

4. Please use the space below if there is any other information that you would like to tell me or you think I should know about the quality of your life since surgery.

01.1 Head and neck cancer is devastating. It affects not only your health and body but overlaps into self-image, appearance, ability to speak and to eat–two very basic and important functions. It is so "out there" you can't hide it under clothes. Surgeons are probably the last people who should be in charge of follow-up care for head and neck patients as they can't seem to address anything beyond a very narrow focus. Head and neck cancer affects a patient's whole life and self-perception.

03.1 It has been really hard for me to get out with my friends much. It seems that so much of my socializing revolves around food. Since it is so hard for me to get solid foods down without water, it takes all the enjoyment out of it. I also have a problem with poor appetite. Another thing that has been a big problem is dry mouth. I always have to be close to water. My sleep is always interrupted because of it.

36.1 The operation on my tongue along with the dryness of my mouth from loss of the spit glands to radiation have confused my ability to control speech and food–my hearing wasn't good when all this started and it has continued to get progressively worse and has affected my personality and my ability to communicate with others.

40.1 The morning after my surgery I took a flashlight and mirror and looked into the roof of my mouth. What I saw <u>did not look right</u>. They did not put enough stitches in and a piece of skin was hanging down. I told them they needed to go back in and sew ot up. Dr. E. E. said it would blend in. It did not. I choked all the time. Dr. P. A. took over and trimmed it off–8 months later. Dr. P. A. was the doctor I wish I had had in the beginning–but it was too late then. At this time I'm sure I have a pin hole in the roof of my mouth and it's just a matter of time till I have more problems–that should have been taken care of on the first surgery.

44.1 It has taken about one full year to get back to feeling normal and being able to do activities I am accustomed to doing. The fact that I can no longer eat some foods because of my lack of saliva is not bothering me much now. I do have to be careful swallowing–my throat is a little constricted.

49.1 The quality of my life is unchanged in any important way. For all practical purposes the only after effect is that I "talk funny" which I ignore and it seems that most other people do too. My eating habits have necessarily changed but there's a good side to that in that my weight is now steady at about 150#s instead of 200#s. I still teach–how they understand me is a mystery–they must pay closer attention. Basically, since I can't do anything about it, I ignore it and just do the best I can do. So far, it seems to be working out OK. I can still look around me and find a lot of people much worse off than me.

61.1 I feel that my operation was a success and am very happy with Dr. C. and the way he handled things. Most of my health problems are due to emphysema.

67.1 I am a full neck breather / stoma. I use an electro-mechanical device to speak. Inadequate volume is a problem. Perhaps I glossed over it, but I saw no questions that directly addressed a feeling of frustration about the inability to communicate in most normal social situations.

Because of this limitation I will avoid larger gatherings of people where noise creates problems. And I'm not talking rock concerts here, but just normal gatherings.

68.1 Because my voice is unreliable I avoid some social situations. Because I sometimes choke when I'm eating I don't enjoy eating in company. I'm not antisocial but I'm more selective about social situations then I used to be. I also guard against excessive fatigue because it takes me longer to recover than it did in the past. I'm sure my age, 84, has something to do with that.

69.1 Removal of a vocal cord causes a lot of pain both physical and emotional. People can't hear me as well and therefore a lot is misunderstood. I am getting stronger as time goes by.

73.1 Even if cancer has taken so much from me and my wife and family I will continue to fight for myself and my family. I feel no strain, no gain and with God in my heart, I'll win.

81.1 My life hasn't changed since my surgery.

99.1 It has been almost a year since my surgery and I am concerned and disappointed that I can't eat (swallow) most solid foods. My wife and I can't go to most of our favorite restaurants or accept invitations for dinner with friends or relatives. We used to go out to dinner once a week–now we can't and I'm sure my wife is unhappy about it. We miss our weekly "date" for dinner out. The radiation treatments (35) have destroyed my mouth. I have very little taste for most foods and consequently don't want to eat. But probably the most annoying thing is the dry mouth. I have to have a bottle of water with me at all times which means I have to urinate quite frequently. At any rate, in spite of these annoying side effects, I am very happy to be alive and Praise God Daily!

107.1 For about a year and a half, I was on an emotional “see-saw.” Feeling depressed and guilty one day and exhilarated and thankful to be alive the next. Now I have a deeper appreciation of my life and the quality of it than ever before. If this survey had come two years ago, I’m sure my answers would have been very different.

122.1 Worst part is not having a support group in a small town. Hard to keep even weight because of reflux. I have a hard time keeping food down.

125.1 It’s not done yet–I still have to face at least one more surgery–recovery is slow so my life will be on hold for another 6 months or so.

40.2 See your spouse suffer during surgery.

44.2 Watching him suffer through surgery and recovery.

47.2 Hard to answer

48.2 Uncertainty of recurrence

54.2 Finding the right food

59.2 Accepting wife's memory loss after a stroke

61.2 Thinking of how I was going to live my life without him.

67.2 The uncertainty–occasionally not knowing precisely what was meant by some terms.

68.2 The period after the Home Health nurses left and I had to run the household and have full responsibility for her physical care.

70.2 The weeks we spent in the hospital after surgery and first few weeks at home.

77.2 The complete experience from beginning to end.

81.2 Getting her to do what she is supposed to do.

85.2 Communication–he would rather nod his head or shrug his shoulders or hold up fingers–instead of using the Newvoice–which he talks very well.

90.2 Watching my husband struggle with recovery from the surgery itself and then adapt to neck breathing.

93.2 His spitting, hacking and coughing up phlegm–no control of saliva during sexual intercourse hence we have none. Extreme hearing loss. Difficulty eating–slurping food.

Spouses' Qualitative Responses

1. Thinking of your experience, what has been the most difficult part for you?

0.2 Lost time with my son.

01.2 Dealing with health care during recovery.

03.2 My spouse has never been a person who showed or conveyed love outwardly. Since this illness, it has become less due to her concern for her well-being.

05.2 Not being fully informed before the surgery–failure of doctors to communicate with us.

10.2 Financial

14.2 Accepting the fact that he had cancer. Worrying about the tube feeding, changing bandages, not making a mistake.

15.2 Watching her recovery after radiation

19.2 The initial diagnosis and uncertainty of how successful surgery would be–the prognosis.

21.2 Seeing him for the first time after surgery.

22.2 Inability of my wife to lead normal active life

34.2 Emotionally

36.2 All of it

37.2 The surgery and recovery

38.2 Waiting for the doctor to talk to me after surgery.

103.2 Knowing how sick and uncomfortable he was, but he would not let me help him in any way. He insisted on doing EVERYTHING himself. I felt useless and helpless.

104.2 My husband's inability to eat normally and to speak clearly.

107.2 Seeing my husband in so much pain and trying to keep his spirits positive at first.

109.2 When he chokes and has to clean his trach

110.2 Surgery and hospital stay.

111.2 Cleaning trach at first come home

117.2 Dealing with his care immediately after discharge and the recurrence of cancer in such a short time (4 months) following radiation treatment.

124.2 Seeing him suffer

125.2 The return of the infection (nobody seems to cure it).

127.2 From the first surgery–the disfigurement of his neck and the loss of voice. He was a singer–was an operatic dramatic tenor–also recited poetry–2nd surgery 19 years later. My hearing is bad. The inability to communicate with him being unable to understand words.

2. What has been the most helpful for you during this experience?

0.2 My husband and I have become closer.

01.2 Having friends to help out until my spouse was fully recovered.

03.2 Our friends

05.2 Friends and family

10.2 Wife's attitude

14.2 Some of the nurses that I called for advice. Can't say enough good about their response.

15.2 Having my faith in God that she would recover

19.2 Regaining a semblance of control by gleaning as much knowledge about his cancer, surgery, etc. as possible.

21.2 The hospice worker at the hospital and the home health care at home.

22.2 My wife's cheerful acceptance of her handicaps.

34.2 keeping a positive attitude

36.2 My faith

37.2 Good doctors and nurses

38.2 Being able to confide in a friend

40.2 My kids and prayer

44.2 All the strength he and friends showed.

48.2 Competence of staff at hospital

54.2 Doctors encouragement

61.2 My husband and his doctor. The doctor was very good to me and my husband kept telling me he was going to be fine.

67.2 Talking to people primarily those connected to health care.

68.2 The surgeon was honest, intelligent and humane without a fault, and the staff was efficient and friendly.

70.2 Information from doctor and New Voice Club.

77.2 To see all the good doctors and God at work–knowing the best will and can be done.

81.2 I had 40 years training in first aid and CPR.

85.2 Family support

90.2 A strong reliance upon the fact that God is in control, and that all He does is good and wise.

93.2 Prayer–church–our family and our doctor.

103.2 His family knows how he is and assured me he was doing things his way because he has always been like that.

104.2 Our insurance company has been a godsend for all we have needed.

107.2 The doctors keeping my husbands and myself up on a positive attitude and being able to be there.

109.2 My support the children give us.

110.2 Family support.

111.2 Family and friends

117.2 Home health nurses and now hospice–they have been wonderful!

124.2 My friends and family.

125.2 Friends and family.

127.2 Understanding from our friends.

3. What advice would you give others who are about to go through an experience similar to yours?

0.2 Confide in others, be open to others support and help–take one day at a time.

01.2 Knowing the right people to contact for help or moral support.

03.2 They had better be strong and hopefully there is enough love in the marriage to hold everything together.

05.2Get as much information from people who have had this kind of surgery.

10.2 Get best doctor

14.2 Just do the best you can–take it one day at a time.

15.2 Turn your life over to God and ask His help. He will answer.

19.2 Learn about the disease; don't allow the rampant horror stories to interfere with hope.

21.2 Don't think it's going to be a snap! It's very gruesome with the leg and neck and all that is included.

22.2 Keep busy. Stay healthy and cheerful.

34.2 To keep an open mind and positive attitude

36.2 Pray

37.2 Find out all you can about what to expect.

38.2 To have a friend or member of the family with you at this time.

40.2 Just be there and support him all the way.

44.2 Always stay "up" and take each day as it comes.

48.2 Go to OHSU hospital

54.2 Work together

61.2 Be sure of your doctor and get 2 opinions from other doctors first.

67.2 Ask lots of questions to understand what is happening. The more you understand the better.

68.2 Get the same doctor and staff even though it is 100 miles from home.

70.2 Hang in there things always get better at least easier to live with.

77.2 Believe in your doctor–and God–all things are possible through them. Never–Never lose that faith.

81.2 Listen to your doctor.

85.2 Take it as it comes. Go with the flow. Discuss future–problems that could arise.

90.2 Trust God. Find a good friend or friends that you can pray with. Be patient. It takes time to heal. Encourage your spouse. He needs to know that you feel confident of his recovery and his ability to handle things.

93.2 Be prepared for physical changes. Be prepared to make adjustments. Maintain one's hobbies and some social things away from home. Do some fun things on your own now and then.

103.2 Try to be as helpful and supportive as you can. Be firm with your help and if they don't want help, they will let you know one way or another.

104.2 Be thankful for the quality of life, any way you can have it.

107.2 Keep a positive attitude and support.

109.2 To be supportive of each other and have high hopes that everything will be OK.

110.2 Get whole family involved in process.

111.2 Take each day at a time.

117.2 I would share our experiences with people and be available to answer questions concerning trach secretions–loss of appetite–foods when lack of appetite–especially since my husband is diabetic!

124.2 Think positive

125.2 Don't

127.2 Pray. Have a sense of humor.

4. Please use the space below if there is any other information that you would like to tell me or you think I should know about the quality of your life since surgery.

03.2 It might be apparent from my answers that there has not been a lot of emotional closeness in our 31 years of marriage. This illness, as well as her serious illness in 1989, have further eroded that situation and her health has become the major priority in our lives.

15.2 When something like my wife's cancer of the jaw bone happens, it changes the whole eating and cooking habits of the house. Because sometimes you are unable to have false teeth in either the upper or lower and combined with radiation, the burning of the mouth makes it impossible to eat right.

19.2 I think that both of us have a much greater appreciation for the health that we may previously have taken for granted. An interesting aside–I was diagnosed with breast cancer and had a bilateral mastectomy with reconstruction. Our surgeries were a month apart–differently, certainly, but I believe it strengthened our bond and our views on healthy living.

21.2 This was difficult because soon after the jaw surgery and radiation which cured the cancer in that area–they discovered lung and liver cancer, so my husband had never gotten a good quality of life back as the chemo he is taking for that has kept him very tired most of the time. Even tho the jaw has healed he has been unable to get appointments after 6 or 8 months to get started with the prosthesis for teeth. All in all, maybe my answers to the survey do not pertain. I feel teeth would have helped a lot –but am afraid it is too late now. He has been a real fighter and followed all the doctor's advice. Maybe in the beginning, if some specialist had been recommended for a good physical, rather than relying on a general practitioner, the other lung and liver cancer would have been caught in time.

40.2 My quality didn't change. I didn't go through surgery.

44.2 We have a very strong marriage and the quality of our life has remained constant with my husband's recovery. With his recovery, we have been able to resume our social life and golfing. Very good friends have cooked food he can eat and given up some meals they might otherwise have served. Dry mouth from radiation is the only long lasting effect my husband has from his cancer. He also has few teeth to eat with but manages very well. At first he could only eat soup, but is now eating everything except green salad and bread.

48.2 We did not understand the treatment or the outcome very well–some aspects were a surprise–scars, sense of taste, speech, loss of feeling. We would not have done anything diffently and the doctor and medical staff were better than our best case expectations in all other respects. Apparently the doctor didn't know either. I guess we were on the edge of what medical science comprehends that's a good place to avoid! –if you can!

70.2 My husband was already disabled, with back injury. He overcame this quite well. Until last 6 months. I think he's not too interested in going on from here.

77.2 The questionnaire took care of just about everything. Thank you.

90.2 I would be remiss in not mentioning that it has been a great encouragement to me that my husband no longer smokes–It was a great addiction for him and a very difficult thing for me to cope with.

93.2 At one period of time I began to fear he was suffering from Alzheimer's. He is confused at times in directions and can't remember things. He was tested about 2 or 3 months ago and proved to be alert which was a great relief to me. I have wondered if the radiation caused some of this problem. We have adjusted to this very well–he can do errands on his own but I'm the primary driver. I can't handle riding with him; he informed me he didn't mind riding with me thank goodness! He also had open heart surgery in 1994. Triple by-pass. Two weeks ago he got atrial fibrillation and was transported to the hospital in the middle of the night. 1:30 am to 4:30 am. Hi primary doctor kept him another day and night for observation and more tests. We are doing fine. He has planted his vegetable garden and many flowers...keeping busy.

117.2 I feel that a gastric pull up is much more debilitating than we expected. No one can even be really prepared for something of this magnitude and my husband's diabetes made it more complicated. Then the fact that we had only been married for 2 years (very happily and sexually active) all made it emotionally very difficult. I am most grateful for my nursing background or I'm sure my answers would not be as positive. I'm doing quite well, tho tired at times–and I still love him very much. Our deep faith in God has made the biggest difference in my feelings.

125.2 My wife and I basically have not had a normal life between the surgeries. We are at the same point of recovery that we were in Sept. 1998.

127.2 The pages I declined to answer I feel were questions which pertained to our marriage / relationship long before the surgery, or have no bearing on his speaking problem. More pertinent to the facts–since his first surgery it was increasingly difficult for him to get work because of the voice problem. Other annoying situations–when asking directions, even though he may be driving, is the reaction of people to think he is also deaf and will look at me to talk. However, we roll with the punches. My spouse has a great sense of humor and often puts people at ease with his jokes about his predicament.